

Hospital Readmissions **From the Inside Out:** Stories From Patients and Health Care Providers

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The issue of avoidable hospital readmissions looms large for health care providers and policy-makers. The federal government reports that nearly one in five Medicare patients returns to the hospital within 30 days—about two million people a year—and that avoidable readmissions cost the government more than \$17 billion annually.^{iv,v} While some readmissions are appropriate and unavoidable, a fragmented health care system and lack of care coordination causes many patients to wind up back in hospitals. Attention to this issue has intensified with the Centers for Medicare & Medicaid Services' (CMS) new *Readmission Reduction Program*, which penalizes hospitals that have too many readmissions. The first penalties were levied in October 2012 against 2,217 hospitals.^{vi} Right now, only readmissions for heart attack, heart failure, and pneumonia patients have been counted, but CMS will be expanding the list of conditions it assesses in reducing reimbursement.

The Robert Wood Johnson Foundation commissioned this effort to look inside the issue of hospital readmissions. This is a storytelling project focusing on patients, families, and health care providers who have experience with hospital readmissions. The purpose of the interviews is to share stories and identify common themes. Many factors are involved in hospital readmissions—this is a complex issue. PerryUndem Research & Communication led the project, which involved interviews with 16 patients who have experienced a recent readmission, four family caregivers, and 12 health care providers who care for patients who have been readmitted. The interviews were held in December 2012 and January 2013 in metropolitan Washington, D.C., New York City, and Dallas. Appendix A provides more information about the participants and how they were recruited.

iv “Community-based Care Transitions Program.” Baltimore, Md.: Centers for Medicare & Medicaid Services, 2001. innovation.cms.gov/initiatives/CCTP/index.html (accessed January 2013).

v Jencks SF, Williams MV and Coleman EA. “Rehospitalizations Among Patients in the Medicare Fee-for-Service Program.” *New England Journal of Medicine*, 360(14): 1418–1428, 2009.

vi Burton R. “Health Policy Brief: Care Transitions,” *Health Affairs*, September 2012, rwjf.org/content/dam/farm/reports/issue_briefs/2012/rwjf401314 (accessed January 2013).

Section Overview

Each patient's story about his or her hospital readmission is complicated, unique, and hard to characterize. Yet there are common traits across all the stories that were shared. Communication breakdowns, for example, seemed to occur frequently. Usually, this happened during the initial hospital stay, often during the discharge process. Instructions were not clear, information was not complete, questions were not asked, and recall of the details was imperfect. Hospitals are not ideal learning environments for ill, medicated patients. Financial pressure to discharge patients as soon as possible also appears to have been a factor. A number of patients felt they were discharged too soon and health care providers agreed this happens frequently. Providers said they face hard questions from hospital administrators if they keep a patient in the hospital longer than the recommended stay. Patient responsibility and compliance also are important factors. Patients who were interviewed may have been too eager to go home and too confident in their ability to care for themselves. Some also went back to work too early, pushed their recovery too much, or did not take good enough care of their health. But they trusted their hospital providers and many did not fully understand the consequences of their actions or could not change their behaviors without additional support.

The health care providers said that discharges can be complicated. They do their best to keep patients from returning, but that does not stop readmissions from occurring. They see a lot of room for improvement. The issue of avoidable readmissions is on their radar and most say hospitals are making changes—better discharge processes, earlier interactions with patients about discharge, and more follow-up care. They also believe the system is fragmented and the hand-off to primary care physicians does not occur as much as it should. Older, sicker patients are particularly hard to assess, said providers, because they “are not going to get better” and it is very difficult to prevent readmissions with this segment no matter what they do.

These and other themes from patients and health care providers are briefly highlighted.

A. Patients

Patients did not necessarily see hospital readmissions as a problem. As compared to the providers who were interviewed, patients and their caregivers seemed unaware that readmissions are very common. Readmissions are personal to patients and they see their experience as unique.

Many patients felt they were discharged too soon. Some of the patients who were interviewed believed that the timing of their discharge was motivated by the hospital's financial considerations. A few patients, however, wanted to be discharged and did not resist even though they still felt too ill to be home.

Many did not understand their discharge instructions. They felt tired, afraid, and “in an alien world” in the hospital. Fifteen minutes of care instruction and pamphlets about their illness were not enough. Those who saw a nutri-

tionist, a physical therapist, and had more time with a doctor or nurse during discharge seemed to do better.

Care instructions were too general. In some cases, discharge instructions lacked the detail patients and caregivers needed once home. Some wished their nurses had told them more about what they should eat and what they should avoid, how to sterilize cloths used to clean an incision, how to inject their insulin, and what the risks were if they stopped their medications.

Patients and caregivers wished they had been more assertive. A number of times during the interviews a patient or a caregiver would say, “Perhaps I should have asked more questions.” Although patients said having a family member or other caregiver present during discharge made a big difference to them, they also said they wish they had been more aggressive in asking questions and pushing for details they clearly needed once home.

New diagnoses posed special challenges. One patient was diagnosed with COPD during his initial hospitalization and felt overwhelmed by the news. He wanted more information, more one-on-one time with his doctor, more hands-on training, and more follow-up care—none of which occurred.

Primary care physicians were missing from the picture. In a number of cases, patients left the hospital and were not seen by their primary care physician or their regular specialist. They give a number of reasons for this, but lack of oversight by their own physician seems to have played a role in some of the readmissions.

Some had only limited or no support once home. Many of the patients were single or divorced men who returned home alone, too weak to care for themselves.

Some were not ready to change behaviors. Two patients admitted they did not comply with care instructions once they left the hospital and engaged in behaviors that put their health at risk and perhaps triggered the readmission. In one case, a patient hospitalized for COPD started smoking again soon after discharge, but argued that he was addicted to cigarettes and his hospital providers should have given him more support to quit smoking.

A few had chronic health conditions for years but were not educated about their illnesses. A number of patients had been battling their chronic conditions for years—illnesses like diabetes and heart disease—and yet lacked information about how to care for their conditions. If they did not receive this information during their initial hospital stay, then they went back to their unhealthy behaviors once home and so caused the readmission to occur.

If their doctor was affiliated with the hospital, outcomes were better. In some stories, it seemed to matter if the attending physician was affiliated with the hospital or part of an outpatient clinic connected with the hospital. When there was not this affiliation, some patients were confused about follow-up care and who to go to when they became sick at home.

B. Health Care Providers

The issue is on their radar. Almost all of the providers said there was new emphasis on reducing avoidable hospital readmissions and knew about CMS' new readmission penalty. These providers said this has caused changes to occur in their hospitals, such as the creation of quality improvement teams, earlier discharge planning, more follow-up care, and better quality information and training given to patients and caregivers.

Readmissions are complicated. Providers point out that a number of factors go into decisions about discharge and that this is a complex issue. If discharging a patient with pneumonia after three days of IV antibiotics and a lowered fever is sufficient in 90 percent of the cases—but in 10 percent of the cases the patient is readmitted to the hospital—should they keep all patients longer than three days? There are often no easy answers to this issue; providers face difficult discharge decisions every day.

There are financial pressures to discharge as soon as possible. While the culture in hospitals may be changing as a result of new readmission penalties, providers say the prevailing pressure is still to discharge patients as soon as possible.

The quality and training of the providers can make a difference. Some providers will think ahead and prescribe medications or treatments to avoid readmissions. But others will not. One oncology nurse explained that he recommends a bowel medication for his chemotherapy patients because they are at high risk of returning to the hospital with impacted bowels. He knows his peers do not necessarily think like he does and they do not prescribe this preventive medication.

Some hospitals are improving the discharge process and in-hospital experience to reduce readmissions. One provider explained that his hospital is starting the discharge process earlier—even while the patient is still in the ER—in order to flag potential challenges and identify information needs. Also, a patient explained that one hospital had him followed by a patient navigator the moment he was admitted. This navigator helped coordinate his care, brought in nutritionists and others to give detailed information, and helped schedule follow-up care to ensure he would not be readmitted.

Some hospitals try to avoid readmissions by referring patients to their own outpatient clinics for follow-up care. As one nurse explained, even when patients have a primary care physician or specialist in another health system, her hospital refers patients to their own clinics and providers for the initial follow-up visit just to make sure that it occurs and that all of the patients' information is transferred.

Findings A. Patient Perspectives

The 16 patients and the four family caregivers who were interviewed range in age, health condition, income, health insurance, and life experiences. Their hospital readmission stories are unique, complicated, and full of twists and turns. The reasons for the readmissions are not always clear and often there are multiple breakdowns and missed opportunities that might have contributed to the outcomes. There are a number of common traits across the stories, however, and these are the focus of this report. What follows are the reflections of patients and, in some cases, family caregivers, on hospital readmissions.

Uncertainty, fear, and suffering are involved in hospital readmissions.

Hospital readmissions take a toll on patients and their families. This is not just a financial or efficiency issue—there is a human impact as well. Patients told stories of being at home, feeling unwell, panicking as their health quickly deteriorated, and wondering if they might die. David, for example, returned home after two weeks in two different hospitals being treated for a pulmonary shutdown that left him unconscious and struggling for breath. He was afraid to leave the hospital, still feeling weak and ill. He recalled being home alone that first night home: “I was real nervous; I didn’t know if I would make it. I thought this might be it.” Barbara, a patient with type 2 diabetes who was originally hospitalized when her blood sugar count reached 500, said she “panicked” when a few days after discharge, her level reached 700. Rather than wait for her husband to drive home from work, she hopped in a cab and returned to the hospital. Having battled diabetes for years, she knew the possible consequences of a blood sugar level so high. For patients like David and Barbara, reducing avoidable hospital readmissions is about more than saving money and reducing waste. It is about their lives.

The hospital is an “alien world.”

Hospitals did not seem to be good learning environments for many of the patients who were interviewed. The patients tried to absorb all of the information and instruction they received but found it hard to retain anything. They were tired, ill, and their minds foggy with medications. When they reflected back on the experience, some said they should have asked more questions or pushed for more time with their doctor. Instead, many said they were unsure what to ask. Those with family members or other caregivers beside them during the key moments of their hospital stay fared better.

The discharge experience varies greatly.

Some patients found the discharge process to be informative and helpful. A few had consultations with dietitians and physical therapists and valued this experience. Some had follow-up appointments made for them while still in the hospital, which they appreciated. One patient, Eric, had his insurance company contact him in the hospital and refer him to a smoking cessation

“I don’t know if you’ve ever been hospitalized, but you try to pay attention but you are in a complete alien area. I was trying. I said, ‘This is my health so I’ve got to take care of it.’”
Ed, readmitted for an infected surgical incision, New York

program when they learned that he struggled to quit smoking. But others felt the discharge process was too rushed, too mechanical, and too general to be helpful. Some believe critical information about their future care was left out. For example, John, who was hospitalized after a severe asthma attack, was not told to avoid long periods outside that could trigger his asthma. An avid gardener, John did exactly that once home, and within 30 days, found himself back in the hospital and unable to breathe. “They didn’t give me any particular instructions about yard work or anything like that,” said John. Ed, with his surgical wound mending, was not warned specifically about reusing compresses and about the risk of infection. Days after his discharge, his knee swelled to twice its size and was clearly infected. Both felt that if they had been given detailed warnings, they would have been “hyper-aware” and could have avoided the mistakes they made.

Many feel they were discharged too soon.

A number of patients felt they were discharged too soon, before they were ready. This was particularly true of the patients with pneumonia or diabetes-related problems. Warren, a patient with diabetes who was hospitalized with dangerously high blood sugar levels, said “I think I should have stayed in there longer because they could only get [my blood sugar level] down to 300. But I think I should have stayed longer so they could have run more tests to see why they couldn’t bring it lower.” Benita, who was battling pneumonia, felt the antibiotic pills she was given when she was discharged were not strong enough to fight her infection. When she returned to the hospital just a few days later, she said the nurse told her, “You probably should have stayed a little bit [longer] because once your fever gets down to a certain point, they think you’re [good].” Benita continued, “I think it was 99 and they think you’re good to go. But I should have stayed.”

A few admit to pushing for discharge.

A few patients admitted they were anxious to leave the hospital and probably pushed the discharge process along. These were patients who knew they were still unwell, but chose to go home anyway. This included Benita, the pneumonia patient, who welcomed her discharge even though she later blamed her hospital providers for letting her leave the hospital too soon. She said, “I was ready to go home because I don’t like hospitals. You know, they’re not my thing.” This also included Mark, who was in the hospital for pancreatitis, and also pushed to be discharged. Both became sicker at home and yet, to their hospital providers, appeared willing and eager to return home. This desire to go home can complicate difficult discharge decisions for providers.

Primary care physicians are missing from the process.

In a number of the patients’ stories, primary care physicians did not play a role. In some cases, the patient did not make a follow-up appointment after their hospitalization or did not go to the appointment even though the appointment was scheduled. Fatigue and weakness were blamed in at least one case. Lincoln, a pneumonia patient from New York, did not feel well enough

“I think one more day of intravenous medication and I probably would have not had to go back.”

Benita, readmitted for pneumonia, New York

“All I wanted to do was lay in bed and sleep [once I got back home], and I knew he was going to ask me to come to his office, and again it’s not hard to get to Manhattan, but when you can’t breathe, the last thing you want to do is sit on the subway with people.”

Lincoln, *readmitted for pneumonia, New York*

for the subway ride downtown to see his doctor. In other cases, patients did not contact their primary care physicians because it was late in the evening when they started feeling ill and they returned to the hospital emergency room on their own. One patient could not get an appointment in the days after her discharge. She was told she would have to wait a month. In about half of the patient stories, there was no primary care physician or doctor who knew the patient involved in the case. This means that there were no opportunities to adjust medications, catch early infections, offer more detailed care instructions, or offer other care that might have prevented a rehospitalization.

New diagnoses are particularly challenging.

Patient information needs seem even greater when there is a new diagnosis. Eric, newly diagnosed with COPD, said he wishes he had one-on-one time with his doctor in the hospital to learn more about the disease and how to care for it. Glenda, a caregiver, struggled with her mother’s new diagnosis of dementia. While dementia ran in the family, Glenda had not recognized any of the familiar symptoms in her mother’s case and wanted the doctor to give her more guidance about whether or not her mother could still live alone, as well as other concerns. In cases like these, when there is a new diagnosis, traditional discharge instructions may not be sufficient and more in-depth instruction needs to occur.

Some with chronic conditions are not educated about their illnesses.

Patients with chronic conditions may pose particular challenges to hospital providers when it comes to discharge. There may be an assumption these patients already know about how to care for their condition even when this is not the case. This situation emerged with two of the patients. Both had diabetes and neither had a clear grasp on what their diet should be, how to adjust their insulin levels, and even how to inject their insulin. These gaps in knowledge could have led to their readmissions.

Lack of hospital staff may be blamed for some readmissions.

David, the COPD patient in Dallas, felt that his initial hospital lacked ICU nurses and that this led to his poor health outcomes. He said he had bedsores and did not make it to the bathroom on numerous occasions because of lack of staff. He complained so frequently that he was eventually transferred to an affiliated “ICU hospital” which was, in fact, probably not the best choice for his care. David said all of his doctors were affiliated with the first hospital but when he was transferred, he lost contact with his providers and again felt his care suffered as a result.

Being alone is an issue.

A number of the male patients were alone after their discharges. They faced challenges as a result. Some skipped meals or relied on fast food. They did not leave their homes. No one was watching for signs of fever or labored

breathing, and no one was there to contact their doctors or 911 as their health declined. Some faced transportation issues as well.

B. Health Care Provider Perspectives

The 12 health care providers interviewed for this project represent both inside-hospital and outside-hospital perspectives. The providers include five nurses (three in hospital settings and two in outpatient clinics), two emergency room physicians, two family practice/internal medicine physicians (both in outpatient clinics and private practices), two hospitalists, and one social worker. All were experienced and knowledgeable about hospital readmissions. Their insights are below.

Avoidable hospital readmissions are a problem.

The providers interviewed believe avoidable hospital readmissions happen too frequently. A family practice physician in New York said, “Probably a third of the patients... come back to the hospital because something happened... it’s high.” Most believe the high readmission rate is a problem—a sign that something is not working well in the health care system. A hospital-based nurse in Washington, D.C., commented, “[It] represents that the system is broken. It represents that as clinicians [we] have things to improve on... it’s a reflection that our patients are not understanding what we want them to understand. And lastly, it also shows that there is poor support in the community to meet our recommendations.” All agree there is room for improvement within their institutions and practices to reduce readmissions.

The issue is on their radars.

All of the providers who were interviewed said hospitals are making avoidable readmissions a top priority. The new penalties for readmissions are the main driver of this focus, according to providers. They said hospitals are now doing things like establishing quality improvement teams and improving their discharge processes—starting discharge discussions earlier in the hospitalization, spending more time with the patient in discharge, having cross-disciplinary teams involved in discharge (dietitians, social workers, physicians), and doing better follow-up care.

Pressure to discharge quickly sends some patients home before they are ready.

Some doctors feel they are caught in a squeeze play. Hospital administrators carefully monitor length of stay—they are eager to send people home because the longer a patient stays the less money they make. Thus, providers said that the prevailing pressure is to discharge patients as early as possible. This can lead some patients to be discharged too soon, before they are ready. A family practice physician in New York explained, “So now [they tell you], ‘Doctor, you cannot keep that patient. Are you having the patient on any IV solutions? No? The patient is drinking, the patient is on pills. The patient has to go home.’ So it’s a lot of pressure also from the hospital to send him

“I think the way the government sort of drives priorities these days is through control of the purse strings... so [readmissions] has become an issue because they’re not going to pay for a readmission in some cases.”

*Internal medicine physician,
New York*

“I think we just sometimes rush them out just too fast. We just need to give it maybe another day. Maybe another two days. Especially when it comes to our cancer patients who have no [white blood cell] counts. You come in with a fever and we give you antibiotics and we will send you home on antibiotics by mouth, which aren’t as strong as what we gave you with the IV.”
*Oncology nurse,
 New York*

home. Patients with just a little improvement, even if sometimes you feel like this patient belongs there still, it’s a lot of pressure because of the economic reasons.” The same physician explained that hospitals frown upon providers who keep patients in the hospital longer than the recommended number of days. He said, “And if you have an unacceptable number of days that your patients stay in the hospital, they’ll talk to you.” On the other hand, providers also recognized that longer stays can also increase the likelihood that bad things, like infections, could happen to patients.

Money drives current hospital discharge policy.

The reasons to discharge patients quickly from hospitals are financial, according to the health care providers who were interviewed, and are a result of the current reimbursement system. An emergency room physician who practices in Virginia explained, “I think hospitals, because of reimbursement issues, are often motivated to get patients out ASAP. So they get a fixed amount of payment for a given DRG [disease-related group] and whether the patient’s in the hospital for two days or 10 days with congestive heart failure, they get the same amount of money. So they want to get the patient out... and they can do that. But what they can’t do is necessarily keep the same patient from coming back to the emergency room a week later with the same problem.” A hospital-based nurse practitioner in Washington, D.C., addressed the same theme when she said, “The length of stay is one of the big buzzwords in the hospital. When you are here 10 days, 15 days, you know people are always looking, ‘How can we get this person out?’ There is the feeling there’s some financial [pressure].” A New York nurse made a similar comment when she said, “It’s just the whole system [pressuring us to discharge too soon]. You know they’ll be saying, ‘Discharge, discharge, discharge.’”

Discharge decisions are complicated.

The providers wanted to make clear that discharge decisions are often complicated with no easy answers. They offered real-life cases as examples of the many factors they must sometimes weigh when deciding whether to discharge a patient or not. A New York family practice physician gave the following example to prove the point:

“I have an 80-year-old lady. She went to the clinic, saw the doctor that was working. She’s 80-something; there’s something wrong. I saw the urine. She had a urinary tract infection, but I don’t want her to be home. She’s 80-something with a lot of medical problems. I sent her to the hospital to be admitted. I followed her. I gave [her] IV antibiotic fluids. [The] urine cleared up but she [might have] pneumonia, too. So we had an X-ray. Everything was clear at that point. I sent her home the following day because I don’t want her to catch something in the hospital. Two days after she’s back in my clinic saying... the cough is bad. So I sent her back [to the hospital]. Now she had pneumonia. So probably she had pneumonia the first

[visit] and we were concentrating on the urine. It wasn't enough. The treatment wasn't enough."

A hospitalist from Dallas also discussed the complex nature of discharge and the difficulty of assigning blame if there is a readmission. He said, "This whole big deal about hospital readmissions, they almost make it sound like it's the hospital's fault or the doctor's fault. I really see the re-admittance more than half the time for other reasons. But they're readmitted because they have significant medical problems. They come in with say, congestive heart failure... I guess to put it in a simple way, their heart is just not working very well. They go home, they don't take their medications, they don't eat the right stuff. They come back in two weeks. Whose fault is that? In the eyes of the public and the government and Medicare, it's the hospital's fault now."

There are few barriers to patients returning to the hospital.

The emergency room physician from Virginia said he perceives few barriers for insured patients to return to the hospital, particularly the emergency room, after they have been discharged. This is particularly true of older and frail patients, who may find it more convenient simply to return to the hospital than wait and see their regular physician. He said, "The resistance to using an ER is very low. You dial 911 and you get delivered right to the doctor's stretcher. But to get to [an office], you know, the office of a private doctor, you got to have a car, the car's got to park, you got to take an elevator." This means that no matter what improvements hospitals make to reduce avoidable readmissions, patients may still return to hospitals in large numbers because they do not face any substantial barriers to doing so.

It is no longer clear who is in charge.

An internal medicine physician from New York said there is substantial confusion these days about who is in charge of the patient once they go into the hospital. This confusion leads to fragmented care for the patient. He explained, "One of the big problems is who takes care of the patient in the hospital and who takes care of the patient when they're out of the hospital? It used to be you were the patient's doctor. If they got admitted to the hospital, you saw them in the hospital and then you saw them a week later. Now there's a hospitalist, now there's the outpatient specialist, now there's the outpatient internist, and then the cardiologist, and then the pulmonologist, and everybody else. And it's difficult for all those people to communicate. And that can lead to readmissions because maybe [the patient] is put on medicine X when they leave the hospital and then when they see their primary doctor or their outpatient doctor, they don't bring their medicines with them even though, you know, maybe they were asked to or maybe they weren't. So you're not sure what they're on exactly."

But some providers argue there is sufficient communication.

Some providers pushed back on the idea that there is a lack of communication and coordination among providers. A family practice physician in New York explained that he is always contacted by the hospital when his patients

are admitted. He said, “I would say, like almost 100 percent of the time when one of your patients, a patient that is under your name, gets admitted in the hospital, they call you. They know me... the attending physician asks the patient, ‘Who’s your primary care?’ And they explain, ‘I have Mrs. so and so; she is here with chest pain and we think we need to admit her or we think that she can go home or she can see you.’” A hospitalist in Dallas explained that he is always talking with his patients’ primary care physicians and other providers. He said, “You know we consult with them all the time, communicate with them. We communicate with the primary care physician when their patient is admitted to the hospital.”

Confusion about medication triggers readmissions.

Some providers said communication breakdowns occur most frequently around medication issues. A medication is changed in the hospital and the receiving physician is unaware and prescribes another medication that conflicts with that medication. Another communication challenge is that patients can become confused when medications are changed and their providers do not fully explain the changes. An oncology nurse in Washington, D.C., explained: “We sometimes prescribe Warfarin and sometimes we prescribe Coumadin [basically the same medication] and sometimes patients get these medications listed on their medication files. So when you have a patient ... they might think that Warfarin and Coumadin are completely different so they take one of each. And as a result they have an adverse effect from the drug.”

Nursing homes press hospitals to release patients who still need care.

A nurse in New York said that nursing homes and rehabilitation facilities apply pressure on hospitals to release patients when they still need significant care. The problem she sees is that these facilities usually lack trained staff and resources to care for an ill or recovering patient. The result is that the patient returns to the hospital a few days later. She explained, “Nursing homes... have their own liaison to the hospital. Sometimes they have eyeballed the patient, they have maybe gone through the record... I had a case recently, the patient has been in and out four times already. And each time somebody [from the nursing home] kept saying, ‘Yeah, we can handle this patient.’ And then a week later, they were back.”

Quality of providers varies on this issue.

Some providers believe that the quality of the individual provider may impact a readmission. Some providers are proactive, thinking ahead, and taking steps to avoid a readmission. But there are some providers who do not think like this. An oncology nurse from Washington, D.C., gave a vivid example of the difference a provider can make in readmission. He said, “If I was your provider and I had given you pain medications and your pain is under control, but however you started to... not go to the bathroom for a week... I need you to eat. You have cancer. [And] if you’re not eliminating it, [it’s] because you’re so impacted and backed up. Well, it’s not uncommon. We have admit-

“I guess lack of education... I guess that could be our fault. If we don’t do a good job educating them on their disease, you know, make sure they understand what they need to do.”
*Hospitalist,
 Dallas*

ted patients who need manual disimpaction. I mean, my practice personally is, if you're on pain medication, I have you on a bowel medication regimen... whether or not you like it [to avoid becoming impacted]."

Patients and family members push for discharge.

Part of the pressure that hospitals face with discharge comes from the patients themselves. A nurse from New York explained, "There's that stubborn group [of patients] that just [say], 'I'm gonna go home and I'm going to do this, I'm fine, I don't need anybody, get out of my life.' [They] bump up and go home." A family practice physician in New York explained, "Honestly, the majority of the patients wanted to leave. The patients that want to stay are rare." In some cases, this can lead to patients being discharged who perhaps were not well enough to return home.

Patients are not always honest.

The nurses said that patients are not always truthful during the discharge process, and they do not always express how they feel about their home situations. A New York nurse, frustrated with the lack of honesty among her patients, said, "Tell me that you understand what I just taught you. Tell me that you understand your medications, don't fib! Don't tell me that everything's fine at home and I have food and I have all that... just tell me, just be more honest." These nurses said that embarrassment over a lack of financial resources is a reason some patients don't speak truthfully. Other patients are just wary and do not like answering questions about their private lives. And some patients just want to be discharged even if they are still unwell and even if they have no support in their homes. Asked to explain why some of her patients are not truthful during the discharge process, the New York nurse said, "I think sometimes people just get a little leery; like why are you asking me all this stuff? Like why do you want to know if I have food in my fridge? Why do you want to know if I can get to the doctor's appointment? You know, so I think some people are just prone to be a little bit more private, they don't want to delve [in] and tell you everything."

The lack of financial resources can lead to readmissions.

Some patients are unable to afford their medications, said providers, and this can lead to readmissions. The family practice physician from New York explained, "You give them a prescription to go buy medication... you know when that happens, they just put it in their pocket and that's it, end of it. People who are not insured, they go home, and usually to maybe no medication, to nothing at all."

Implications and Innovations

The patients, family members, and health care providers told stories that show the complexity of hospital readmissions. There are no clear-cut, one-size-fits-all answers. And yet each story seemed to present opportunities to take action that could have led to a better outcome. Below are ideas that arose

from comments that patients and providers made in their stories. Many, if not most, of these ideas are being pursued in hospitals across the country.

Plan for discharge earlier.

According to many providers, hospitals are already doing this. An emergency room physician from Virginia explained, “[The hospital] is getting very much more proactive on discharge planning. In fact, they start discharge planning, not within minutes, but very soon after a patient gets admitted.” Starting earlier may give patients more opportunities to ask questions and retain the information.

Offer more intense education for new diagnoses.

The patients and families who received new diagnoses during the initial hospital stay had substantial education needs that a traditional discharge process or consult with a physician will not be able to address. It would be helpful to flag these needier patients and connect them with more intense instruction and programs before they go home to reduce the likelihood of their returning to the hospital.

Flag high-risk patients and provide case management.

Two patients in the Washington, D.C., region appeared to have experienced case management during their second hospital stays and felt this made a difference. Both said they were assigned case managers/navigators as soon as they were admitted and that these individuals followed their cases and provided care coordination throughout the entire stay.

Take a multidisciplinary approach to discharge.

The hospitalist from Dallas explained that his hospital has a team approach to discharge to cover the range of needs a patient might have. He said, “Every patient who smokes, [they get] smoking cessation. If they’re diabetic, we counsel them on diet, weight loss, exercise. If you come in with heart failure, we counsel them on keeping the weight [down] once they get home, low-salt diet. That’s our job. That’s what we do when they’re discharged from the hospital.”

Check in with patients with chronic conditions.

At least two patients had big knowledge gaps when it came to caring for their chronic illnesses. Because they both had these conditions for a long time, they did not seek out new information and their providers did not offer it during the initial hospitalization. As a result, both returned to the hospital with their conditions still out of control. Patients with conditions like diabetes and COPD could use a check-in during their hospital stay to make sure they know the basics about their illnesses.

Arrange follow-up care.

In some of the patient stories, there was little or no follow-up care with a medical professional after the initial hospitalization. This caused problems. There are many reasons for lack of follow-up care and patients take some re-

sponsibility for failing to follow-up care despite the best efforts of the hospital to schedule an appointment. However, maybe there is more that hospitals can do. For example, a nurse in New York explained that she arranges follow-up visits for each of her discharged patients through the hospital's own outpatient clinic—even if the patient has his or her own primary care physician. The hospital does this to make sure there is follow-up care and oversight once the patient leaves the hospital. They also feel more confident that the patient's information—like medications and hospital records—will be communicated to the clinic provider.

Reconnect with primary care physicians.

The providers asserted that hospital-based providers are, in fact, reaching out to patients' primary care providers when they are admitted. But a number of the patients said they were not in contact with their physicians either during or after the hospital stay. This may be due to the rise of hospitalists and the fact that primary care doctors are less likely to spend time in hospitals visiting their patients. Whatever the reason, it seems critical that primary care physicians reconnect with their hospitalized patients.

Monitor physician readmission rates.

Providers said just as hospitals seem to monitor physicians who keep patients in the hospital “too long,” it may prove useful to monitor those who have high readmission rates. Given the readmission penalties and the money now attached to this issue, it is likely hospitals already are monitoring readmission rates of their providers.

Offer more training for providers.

Providers said their colleagues vary in quality and this may be impacting readmissions. It seems essential that provider training focus more intensely on this issue in the future to reduce the variance that providers said currently exists.

A Patient's Story: Lincoln

Readmitted for Pneumonia

Lincoln is a 50-year-old African American man living alone in an apartment in Queens, N.Y. He lost his full-time job with the downturn in the economy and is currently working part-time. Lincoln has Medicaid coverage. His health is “pretty good now,” but he is at risk for esophageal cancer and must be checked yearly for cancer cells in his throat. He also takes medication for acid reflux.

Lincoln has battled pneumonia once before so he knew the symptoms when, in June 2012, he started coughing, found walking difficult, and could not catch his breath. He called 911 and was taken to a local hospital. The hospital was not his first choice—he had a previous negative experience there before, but felt he had no choice since the hospital was closest to his home. He said, “I knew it was going to be a nightmare” when he learned he would be going to this hospital. He was admitted through the emergency room, treated with IV antibiotics, and released after three days. Lincoln felt it was too soon to be released. He said, “I don’t know if they pushed me out because they needed the space, [or] if they pushed me out because I’m on Medicaid and I’m not paying as much as private insurance.” The last time Lincoln was treated for pneumonia (at a different hospital), he was there for six days, so “it was kind of weird” to be released after three days.

During his initial hospital stay, he felt the nurses were “horrible” and overworked. He felt he did not have time with his doctor. He believes his caregivers—the doctor and the nurses—did the “bare minimum” in terms of care for his pneumonia. Since it was a teaching hospital, his doctor came to his hospital bed with his students and discussed his case. He told Lincoln he would increase his antibiotics and gave him his discharge date. Lincoln wishes he had more time to talk alone with the doctor. “You know, in retrospect, I could think of some things to ask, but when you’re sitting there and you are out of it... you want to hear [the doctor] but you also just want to sleep and be left alone.”

Lincoln called his primary care doctor to tell him he was in the hospital. The primary care doctor asked Lincoln to come to his office once he was discharged so he could check on his recovery. But Lincoln did not make that appointment. He said, “All I wanted to do was lay in bed and sleep [once I got back home], and I knew he was going to ask me to come to his office, and again it’s not hard to get to Manhattan, but when you can’t breathe, the last thing you want to do is sit on the subway with people.”

“In my mind, I wasn’t quite ready [to be discharged] but I’m not a medical guy.”

Lincoln, Readmitted for pneumonia, New York

Lincoln did not have an informational discharge process. “Okay, you’re going to go home today, we’re going to discharge you’ and then that was the last I saw of him,” explained Lincoln. He said eventually the nurses came in and gave him some prescriptions, and then he signed some papers. That was all. He recalled that they told him to continue his medications until they were done, even if he was feeling better. But Lincoln did not feel well enough to go home yet. He trusted his doctor when he told him that he was getting better and so went along with the discharge despite his misgivings.

Lincoln left the hospital with three antibiotic pills and a prescription for more. He filled his prescription at his local pharmacy. Once home, alone in his apartment, he mostly slept the next two days. He explained what happened next: “In about two days, I was in that same state. I couldn’t walk from here to here without sitting down. So I called the ambulance again and they took me back.” He went back to the emergency room; they realized he had pneumonia and gave him oxygen and IV antibiotics, and after a six-hour wait for a bed, he was readmitted to the hospital.

Lincoln was in the hospital two days the second time. He said that he felt “much better” after the new round of IV antibiotics and the oxygen. He believes the readmission would never have happened if the hospital had just kept him five or six days during his original hospital visit. He was told that the IV antibiotics are more effective than the pills he was taking. He concluded that a few more days with the IV medications would have made the difference.



A Patient's Story: Barbara

Readmitted for High Blood Sugar

"I would have liked it if they told me what I could do better to take care of myself. Because maybe I'm doing something wrong. Sometimes I might skip meals and then when I do eat, I'll eat the wrong things. I would have liked to maybe speak to a nutritionist, something like that."

Barbara, readmitted for high blood sugar, New York

Barbara is a white, 44-year-old woman who lives in the Bronx, N.Y., with her husband and four children. She has worked as a child care provider for the last 10 years. Barbara is "dealing with a lot of health issues." She has type 2 diabetes and says it has caused nerve damage and constant pain. She also suffers from sleep apnea, high cholesterol, and thyroid disease.

Although diagnosed with type 2 diabetes in 1998, Barbara has large gaps in her knowledge about diabetes management that surfaced when she was hospitalized a year ago. Not once did she recall having a serious discussion about her diet with her primary care provider. She explained that she went to the emergency room when her blood sugar reached 500. She did not call her doctor first because it was late in the evening and she figured he would not answer. Barbara was admitted to the hospital and stayed for two days. She said that doctors in the hospital gave her saline through an IV to "kind of clear me out" and also insulin and put her on a diabetes meal plan. They took her blood sugar count three times a day. After two days, the doctors felt the count was "pretty stable" and they discharged her. Barbara questioned whether she should have been discharged so soon. "I don't think [my counts] were stable... because they were still pretty high."

Barbara's primary care doctor visited her during her initial hospital stay. Her emergency room doctor had asked who her primary care doctor was and contacted him. The primary care doctor told Barbara to make an appointment once she was discharged so that they could develop a new care plan.

Barbara said the discharge process from the hospital was not as detailed as she would have liked. She explained that the hospital doctor stopped by her room and just told her to "watch what I'm eating" and that "everything is under control now." She said a nurse gave her a little more detail, "Like no sugars, no sodas, no candy, no sweets." Barbara wanted more information and to "maybe speak to a nutritionist." But she trusted her doctor and went home.

Once home, Barbara contacted her primary care doctor's office to make an appointment, but was told their earliest opening was a month away. Even after explaining she had just been discharged from the hospital, she still could not obtain an earlier appointment. Barbara was fine for the first day and a half at home, but started having terrible headaches. She checked her blood sugar and found it was 700, a number she said is "dangerously

high.” Barbara explained, “I panicked, I had never seen that before.” She hopped in a taxi and went straight back to the hospital.

The second hospital stay lasted two weeks. During the second visit, Barbara was given a new kind of insulin. Her doctor told her that her body had become accustomed to the old insulin and that she needed to change her dose. Her hospital doctor also recommended that she start seeing an endocrinologist since she has multiple chronic health conditions in addition to her diabetes. No one had told her this before. Barbara also met with a nutritionist—something she had wanted during her initial visit—and learned during this consultation that many of the foods she was eating were bad for her, like white rice. After two weeks, Barbara was feeling better and ready to go home.

Once home, she finally had her appointment with her primary care doctor. It was her primary care doctor who taught her how to adjust her own insulin amounts and instructed her on how to correctly inject insulin. She thinks if she knew this information before, she could have possibly avoided the hospitalizations. “If I would’ve known [before], maybe I could’ve added a little more units to get [my blood sugar] down,” said Barbara.



"FOLKS WITH NEW
DIAGNOSES SHOULD
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DOWN, ONE-TO-
ONE DISCHARGE."
ERIC, READMITTED
FOR DIFFICULTY
BREATHING
WASHINGTON, D.C.

A Patient's Story: Eric

Readmitted for Chronic Obstructive Pulmonary Disease (COPD)

Eric is a 51-year-old African American man who lives alone in Washington, D.C. Eric retired from social work early due to a disability and works part-time as an usher at a local theater. Eric has a number of health challenges.

Back in May 2012, on Eric's 51st birthday, he was struggling to breathe. A friend had given him a ride to renew his driver's license and became worried about Eric when his breathing became labored. On the ride home, Eric told his friend he needed to get into his house because, "I knew that I wasn't right." Walking up the flight of stairs was difficult and once inside his home, Eric found it difficult to undress. A longtime smoker, Eric had never had such difficulty breathing before, but wondered if this was caused by his smoking. By 2 a.m., Eric still struggled to breathe, and called his best friend to take him to the hospital.

Eric's primary care physician is affiliated with a hospital so he chose to go there. He had been to this hospital before and felt comfortable there. In the emergency room, Eric had a CT scan, some X-rays, and received oxygen. He was admitted to the hospital for five days and during this time, Eric received a "whole lot of breathing treatments and just tr[ie]d to absorb the new information [of] a second chronic disease to carry."

It was during this first hospital stay that Eric was told he has COPD. While Eric felt that his smoking was to blame, he did not spend time on regrets. "I don't know I just... I just thought it would be extra strength if I took the guilt trip. You know, and that would be added weight that I don't necessarily need." What Eric was interested in, however, was information about caring for his new chronic health condition. He felt his doctors did not give that to him. Describing the instructions he received, Eric said, "Just a whole lot of doctors going, 'You shouldn't smoke!'"

For Eric, it is important to feel a connection with his doctors. He has been battling a chronic disease for a long time and believes he gets better care when he has a personal connection. The challenge for Eric was that his primary care doctor was out sick while he was in the hospital and was not involved with his care. Eric did not feel a connection with the hospital doctors caring for him and was frustrated that they did not give him more information about his illness, especially during discharge. "The hospitals in general need to be a little more actively involved [with their patients]. The doctor, not the nurses, but the doctor should be involved personally."

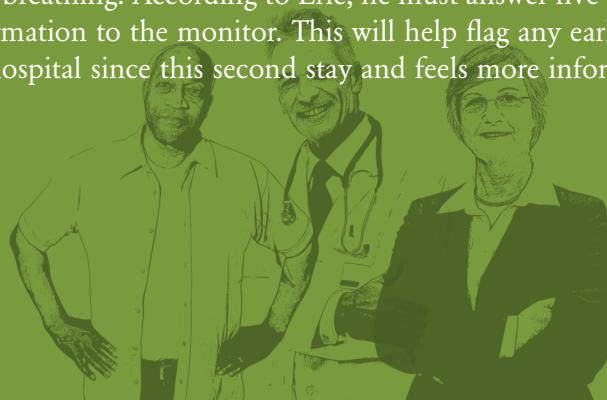
This impersonal, uninformative discharge process frustrated Eric because “I had millions of questions.” Feeling uninformed about his COPD, Eric said he was “really scared to go home, but I knew I had to go home... I didn’t know how it would turn out.”

Once home alone, Eric’s labored breathing limited his ability to care for himself. With no energy, he bought prepared foods. Without care instructions, he was unsure if he should be exercising or not and said he had gained 20 pounds since his diagnosis. He also struggled with his smoking—limiting it but not giving it up completely, despite knowing it could harm him. Eric also had a new inhaler but no one explained when to use it. Eric did see a pulmonary specialist soon after his hospitalization but felt it was too soon after the diagnosis to really benefit him.

Eric returned to the hospital about 30 days after his discharge, once again for breathing problems. Feeling he was recovering from his initial hospitalization, Eric took a five-day trip to Las Vegas during which time he smoked, endured 115 degree temperatures, and generally did not take care of his health. Eric knew he was ill when he returned home but decided to wait until a scheduled appointment rather than rush to the emergency room.

This appointment was with a new pulmonary specialist, one who was attached to a different hospital. In that appointment, the specialist decided to admit Eric to the hospital right away because, as Eric explains, “I couldn’t breathe. I was coughing all over the place.” This was a different hospital from Eric’s first breathing episode. This time, Eric was assigned a “navigator” while in the hospital—a patient advocate who followed Eric’s case and helped identify and coordinate his care needs. Eric made a personal connection with his navigator, who “knew me, knew my family.” He also connected with his doctors this time around, who “held my hand and made eye contact.” While in the hospital, the doctors changed his inhaler and medications and Eric believes this has helped improve his health.

Eric’s health insurance plan became involved during this second hospital visit as well, calling him and discussing various resources to support his health. Through this contact, Eric was referred to a smoking cessation program and was sent information about his COPD. When Eric was discharged, he was sent home with a small wireless monitor to help him track his breathing. According to Eric, he must answer five or six questions daily about his breathing and input this information to the monitor. This will help flag any early signs of breathing problems. Eric has not returned to the hospital since this second stay and feels more informed and secure now about his COPD.



A Patient's Story: David

Readmitted for a Pulmonary Shutdown

David is a 53-year-old white male who lives in the Dallas area. David's health coverage comes from Medicare (because of his disability) and private insurance. He was diagnosed with muscular dystrophy when he was 17 years old and says the symptoms did not start affecting him until his mid-thirties. David was ambulatory until he was 47 years old, but now relies on a motorized scooter for his mobility.

David explained that his health was good until 2007. "I was like a normal person." The combination of a stressful job, poor diet, and smoking led to cardiac arrest during that year, however. Since that time, David says his overall health has declined. His biggest challenge is that each winter, David comes down with pneumonia and is usually hospitalized for a number of days until his lungs clear. "Any small cold can turn into something very deadly for me."

In May 2012, David was hospitalized once again. He said he had felt ill all week and then suffered a "pulmonary shutdown" in his home. A friend happened to be over that night and noticed that David did not look well. After David went to bed, she checked on him and saw that his lips were blue and that he was unconscious. She called 911. "The next thing I remember is waking up, tied to a bed, there was a big breathing tube down [my throat]. I can't talk, pray, and I was on a ventilator," said David.

David was in this hospital for about nine days and did not like the care he received. He explained, "They had this new deal where they don't have enough nurses in the ICU and so you wake... and you are screaming... and they got a TV screen [instead of nurses]. It's just terrible." David explained that the TV screens were part of a monitoring system the nurses use to observe patients in the ICU. David would have preferred more human contact during this period and he complained to his doctors. "I told them, 'You are not taking care of me, I push my button, I push my button...' I was getting sores on me from laying in my own stuff."

David was transferred to an affiliated ICU hospital where he was told he could receive more care. He was there for five days and once again was disappointed in the care. While his cardiologist and pulmonary doctor visited him at the first hospital, David said he did not know any of his providers at the new hospital and felt alone. "I know I was weak and I couldn't move... you think that they're going to do more damage than they're going to do good. You lose all faith in them... because I knew nobody."

"I didn't know a soul, no specialist to come by, my cardiologist didn't come by. I can't even tell you who was in control."

David, readmitted for pulmonary shutdown, Dallas

Although weak and still ill, a nurse asked him if he felt ready to go home. David responded “no.” When asked if there was someone at home to look after him, David told the nurse about the tenant who rents a room in his house. David said the nurse did not suggest a visiting nurse check on him and he did not even know if his insurance would have paid for it. David did not feel ready to go home and feared he might die once home. “I was real nervous, I didn’t know if I would make it. I thought this might be it.” The hospital discharged him anyway.

David was only home one day before he knew he was too ill to be there. “I just couldn’t, I mean I still wasn’t breathing.” David felt he could not rely on friends for all of the help he needed at home in his weakened state and with his mobility issues. “I got to feed [myself]... some people work, you know I can’t expect [my friends to do everything]. I couldn’t even always get to the bathroom.” This time, David called a private ambulance so that he could choose his hospital—a teaching hospital that is a farther drive from his home—rather than return to the two hospitals he had recently visited.

David did not contact his cardiologist or his pulmonary specialist during this time period because he was afraid they would send him back to the first hospital, where they both have privileges. He thought they might say, “If you feel worse, come back to the hospital.”

David was happy with his choice of hospital this third time around. “The nurses were a lot nicer. Their pulmonary person came in, looked at me, and took X-rays, and said, ‘You got a pulmonary plug, as she called it, and she described it as a man-of-war, you know those things that float in the water, got little tentacles... She goes, ‘You got to get that out of there.’”

David explained that the pulmonologist at the first hospital had talked about looking in his right lung to see if there was a blockage, but was thankful this new doctor pushed for the procedure and actually removed the plug. Almost right away, David said his breathing improved. A nutritionist visited David during this third hospital stay and explained about ways for David to improve his diet. She also explained that certain foods aggravated David’s breathing issues—some of which are complicated by his muscular dystrophy—and made him feel like he could not catch his breath.



"Now there's
a push to make
that appointment
from the hospital
for the patient
and send them
out with that."

Glenn, internal
medicine,
New York

A Provider's Story: Glenn

Internal Medicine, Outpatient Hospital Clinic, New York

Glenn is an internal medicine physician who works at an outpatient facility in an academic hospital in New York. He explained that at the clinic, he runs pre-surgical testing, sees his regular patients, supervises residents, and plays a role in the quality improvement department.

Glenn explained that the issue of avoidable hospital readmissions is becoming more of a priority at his affiliated hospital. "I think the way the government sort of drives priorities these days is through control of the purse strings... so [readmissions] has become an issue because they're not going to pay for a readmission in some cases."

But he says this is a complicated issue and that physicians like him feel cross-pressured. "Based on DRGs, the hospitals try to get the patients out as soon as they seemingly can. On the other hand, if you send somebody home after three days and 90 percent of the time that's enough for them, but 10 percent of the time they're going to decompensate and have to come back in two more days, then if you kept everybody for those five days, maybe none of them would come back and you have no readmissions."

Providers like Glenn seem to be playing the odds each time they discharge a patient. He gave an example of a heart failure patient to show how difficult it can be for a provider to make the right discharge decision. He said, "Let's say heart failure, for instance... if someone comes in and they've got too much fluid in their system and you give them medications, and you get them to get rid of some of that fluid, you may say, 'All right. You know it seems like they've probably gotten rid of enough and if they go home now, as long as they keep up their diet and take their medicines, they probably won't need to come back.' And in most cases, that may be true. But it may be that the patient is going to stop their medicines or not going to comply with their diet, which is frequently the case. And if you send them home [as soon as] you can, then you don't have that much of a margin of safety. If you kept them an extra day or two, maybe get rid of more fluids... they may go home that far away from decompensating. And they'd be less likely to be readmitted if you kept them a couple more days."

Glenn also understands that it is challenging for patients to absorb instructions in the hospital and be able to follow them once home. He said,

“It’s hard to give patients instructions and it’s hard on the patient’s end to listen to instructions and to remember everything you’re told. You know, just waking up from anesthesia, or it’s a week before the surgery and you’re nervous about the surgery. You have other things on your mind and you know you’re being told a whole bunch of things that you don’t have a context to put them in because you’re not really trained in that. And... it’s hard to remember things if you don’t know... you’ve never seen a wound before; you’ve never seen any of that.”

But Glenn saw positive change occurring on this issue. At the hospital he is affiliated with, there is more effort to refer discharged patients to outpatient providers to ensure there is follow-up care and possibly avoid a readmission. He said, “There is the theory that if somebody’s seen soon, within a few days of being discharged, then if they’re decompensating or look like they’re heading toward getting readmitted, the outpatient doctor may be able to do something to head that off.”

He also noticed a stronger push for follow-up care more generally. Glenn explained, “So there are initiatives, for instance, to make sure... so generally when the patient’s discharged, you would ask them in the olden days to make an appointment with their doctor within a week or two weeks. It was found that many times the patients either felt that they felt okay or for whatever reason, they didn’t make that appointment. So now there’s a push to make that appointment from the hospital for the patient and send them out with that.”



Appendix A: Profile of Participants

		Patients	Caregivers	Health Care Providers	Total
Gender	Men	12	3	7	22
	Women	4	1	5	10
Age	30–40	2		3	5
	41–50	5		5	10
	51–64	7	2	3	12
	65+	2	2	1	5
Race	White	6	1	8	15
	Black	7	3	2	12
	Latino	3		2	5
Health Condition	Pneumonia	4			4
	Heart-related condition	4	1		5
	Surgery/post-op	3			3
	COPD/respiratory	2	1		3
	Diabetes	2			2
	Other	1	2		3
Insurance Type	Employer	11			11
	Medicare	4	4		8
	Medicaid	1			1
Type of Provider	Nurse			5	5
	ER doctor			2	2
	Internal Medicine/ Family Practice			2	2
	Hospitalist			2	2
	Social Worker			1	1
Years in Practice	1-4			1	1
	5-9			2	2
	10-19			6	6
	20+			3	3
Total Participants		16	4	12	32