When nurse Janis Hovorka first visited at her home in rural Maine, Irene barely let her past the front door.
“She told me right off, ‘I don’t need any help,’” says Hovorka, a patient care manager for the Kennebec Valley Community Care Team in Maine. “She even gave me an example: She shoveled her deck in the wintertime, though she walked with a cane.”

Irene, who had multiple health problems and substantial hearing loss, was a prime candidate for KVCCT’s services targeting “super-utilizers”—patients who make frequent trips to the emergency room and have many hospital admissions. They are the one percent of the population that, according to a 2012 report from the Agency for Healthcare Research and Quality, accounts for 20 percent of the nation’s health care costs, and the five percent that accounts for 50 percent.

Irene had also been missing medical appointments. Her doctors wondered if she was really taking her medication.

The meeting went downhill from there. But then Hovorka noticed a plaque on the wall that mentioned Irene’s tenure as president of the local historical society. Hovorka asked about it; Irene opened up. Pretty soon she was talking about other things: her younger years with an abusive husband, the fact that she had very little family and couldn’t hear well enough to use a telephone, her desire to lose weight.

Hovorka was able to help Irene get on a walking routine, sign up for Meals on Wheels, and get hearing aids through a grant program. “She really lived a different life because she wasn’t struggling to hear everybody, including the doctor,” she says.

Hovorka told Irene’s story at the Robert Wood Johnson Foundation’s Super-Utilizer Summit in Chicago last summer. The Summit brought together leaders of six Aligning Forces for Quality sites around the country working on pilot projects to reduce emergency room visits and hospitalizations for “super-utilizers,” a small group of patients that disproportionately strain the health care system.

Often destitute and alone, these patients need help figuring out where to go and how to get health care so they’re well-cared for and no longer require frequent visits to the ER.
Super-utilizer patients fall into several different categories—from patients with chronic conditions to those who struggle with behavioral health needs that impede their ability to engage in self-care, to frail elderly patients.

In some instances, addressing health care needs isn’t enough on its own—some patients may lack access to phones for providers to check in on them, while others may have trouble keeping their lights on. Some are isolated because they live in remote areas or lack a network of family and friends nearby.

At last summer’s meeting, representatives from the six sites—Maine; Cleveland; Humboldt County, Calif.; West Michigan; Greater Boston; and Cincinnati—shared strategies, struggles, and success stories for meeting the complex needs of the patients they work with.

Jeffrey Brenner, MD, executive director of the Camden Coalition of Healthcare Providers, provided big-picture perspective, addressing lessons learned across the sites and better ways to track data and broaden the scope of these pilot projects.

When Brenner began gathering data from hospitals and mapping health care use across Camden, N.J., in the early 2000s, 13 percent of patients accounted for 80 percent of hospital costs in the impoverished city. He and other primary care providers in the coalition began building relationships across the health care system—from hospitals to social workers and government agencies—to find better ways to care for these super-utilizers.

The six pilot Aligning Forces projects, funded by RWJF, grew out of Brenner’s work.

“These pilot projects really build on the work the Alliances are doing in their communities to improve the equality and the value of health care and to decrease disparities in their communities,” says Susan Mende, BSN, MPH, senior program officer for RWJF. “If you want to address quality, value, and disparities, you have to look at better ways of providing care for this group of patients.”

The differences are profound. In Cleveland, low-risk patients cost the health care system about $2,000 a year each. High-risk patients cost on average $54,000 a year each, says Alice Petrulis, MD, clinical champion of the Red Carpet Care program at MetroHealth.

BUILDING PATIENT TRUST

Irene’s story hit on a common finding among the six sites: providers need to build a relationship with the patient, to go to where they are. In Cleveland, patients without phones received cell phones with a direct line to their caseworker. In Boston, health outreach workers and nurses visit patients in their homes or in community settings.

Another theme that emerged across the sites is the importance of a thorough screening process with set criteria for patient referrals. If you base your screening on recommendations from primary care doctors, or ask the frontline staff to decide on a case-by-case basis, “you may find yourself in a deep hole,” says Brenner. Both Maine and Michigan have refined their screening criteria so they’re not basing referrals on word-of-mouth.

Suzanne Cole, nurse care manager for the Maine site, says that it’s important to make sure the goals for the patient and the goals for the project are in tandem. The Maine team maps out a patient’s discharge plan from the beginning. “If you don’t have a good reason to admit somebody, there’s not going to be a good reason to discharge them,” she says.

In 2011, Cole began working with “Joe” (who asked that his last name not be used). That year, Joe, whose health issues were complicated by a history of alcohol abuse, made 18 trips to the emergency room.

Cole and others met regularly with Joe over time, helping him manage a diabetes diagnosis with a careful diet and exercise regimen, and giving him travel vouchers so Joe, who does not own a car, could attend appointments. Since joining the program, Joe has maintained his sobriety and effectively managed his diabetes through diet and exercise while making only two trips to the emergency room—and is close to receiving a formal discharge.

“Joe went from one extreme to the other,” Cole says.

Many sites also brought up the need to treat behavioral health with this group of patients. Corey Waller, MD, director of the Center for Integrative Medicine in Grand Rapids, Mich., says that nearly all of the super-utilizers they see in West Michigan have experienced trauma.

“Going forward, the lesson learned is really how that piece of trauma informed care and just how important the mental health of that person is,” Waller says. “We find almost a direct correlation between early life trauma and the development of the maladaptive thought processes these patients have.”

In its first year of the RWJF grant, the Center for Integrative Medicine took on 418 new patients, at a total cost of $866,042 for their care. They’ve seen a 25 percent reduction in hospital charges for these patients.

Care coordinator Pam Crider, APN, from the MetroHealth System in Cleveland, talked about a home visit that really brought out the importance of addressing behavioral health. The visit was going fine—“we were having a nice discussion”—when the young woman asked if Crider would like to see her daughter’s room.

“I said, ‘Where’s your daughter?’ and she said, ‘Oh, she’s dead.’” Crider’s medical background didn’t prepare her to counsel the woman. But the behavioral health specialists on the team, “gave me ideas on how do I proceed from here.”
Many patients come in with a staggering number of diagnoses, some of which are wrong or are side effects from all the medications they’re taking.

Waller recalls a patient who was on 37 different medications and had 22 different medical diagnoses the first time she was seen by the clinic.

“Sixteen of those were wrong and were actually side effects of the medications she was on,” he says.

**DIFFERENT COMMUNITIES, DIFFERENT CARE MODELS**

Each site has a different model of patient care. In Maine and Cleveland, teams work directly with the patient and care is centered on a patient-centered medical home.

In Cleveland, super-utilizer clinics are embedded within primary care practices. The Cleveland team worked directly with the regional health plan in identifying super-utilizers and kept the payers in the loop with biweekly meetings.

West Michigan has an integrative team approach centered around a multi-specialty clinic staffed by a physician, mental health worker, researcher, and physician assistant that specifically treats super-utilizers throughout the area.

Cincinnati’s ED Care Coordination Pathway Program Pilot uses community health workers and AmeriCorps workers to coordinate services and support patients through medical, social service and behavioral health services, while a multidisciplinary team of physicians, case managers and behavioral health staff oversees their care.

In Greater Boston, a community-based medical center works within a large academic medical center. The team consists of a health outreach worker, a nurse, and a “clinical champion”—often a physician in a primary care practice. The health outreach worker and nurse meet with patients where they are—usually in their home or a community setting—to figure out what their primary needs are and the barriers to care. The team works with patients for around 48 months, then moves them into other supportive care systems.

Humboldt County, a rural community in a remote part of northern California, has a “warm hand-off” system from a Care Transitions Program at St. Joseph Hospital—which pairs discharged patients with coaches that evaluate and help manage their care—to a community-based primary care program. A multidisciplinary team that meets regularly to discuss the patients includes primary care providers, nurse care managers, community clinic staff, and emergency department clinicians.

While each community is approaching their super-utilizer population differently, there are key themes that have emerged from the six sites:

- Collaboration is an important part of this work. Small communities have a much easier time with this.
- It’s easy to get stuck in the planning. The most successful programs tinker and adjust the model as they go along.
- Successful sites have a love for project management and clinical skill sets; sites heavy on clinicians and light on project management have it harder.
- Care teams need different models for different types of patients—emergency room super-utilizers vs. inpatient super-utilizers, etc.

**LEARNING FROM PATIENTS IS KEY TO SUCCESS**

Some sites have been up and running for two years, giving the teams some time to tweak their model and come up with new approaches to treat their patients.

To figure out what super-utilizers really needed and how best to reach them, the Cleveland team set up focus group discussions with patients from IMPROVE, a state-run Medicaid program. Patients talked about the importance of their relationship with their case manager over their doctor in learning about their health care options—a perspective that surprised some of the team members—and that they were most likely to change unhealthy behaviors if the doctor looked them in the eye and said it was important.

“Too often they don’t really get in that position where their social qualms and behavioral issues are set aside and they’re just talking with the doctor one-on-one, person-to-person,” says Brad Lucas, MD, chief medical officer for the Buckeye Community Health Plan, one of the payers on the Cleveland team.

The Maine team found that the first time they did a focus group with these patients, nobody wanted to participate. They decided to bring in a therapist and talk about what patients were afraid of—“‘What’s the worst thing that could happen to me?’” says Waller.

In Humboldt County, a “big win” this year was adding a super-utilizer nurse to the care transitions team. The RN, a long-term ER nurse, is embedded in the emergency room, where her job is to identify super-utilizer patients right at the point of care. She knows many of the patients well and is able to assess whether to admit them to the ER or work with the care transitions team to figure out another course of treatment for them.

The Humboldt super-utilizers have gone from 160 annual emergency department visits...
to 60 annual visits in a six-month period.

COLLABORATION HAS ITS CHALLENGES

Henry White, MD, a member of the Boston team and clinical director of the Brookline Community Mental Health Center, talks about the challenges of working with large academic centers on a super-utilizer project.

“Boston is very rich in lots of medical services, but as you can imagine, for our patients, it was hard to get the services they needed when they needed them,” says White. “We’re a very small community-based medical center. We work in people’s homes and we have a very friendly outpatient facility and now we’re in a very large hierarchical academically-focused medical center. We have lots to learn from each other in an honestly bumpy journey.”

The very large primary care practice they worked with included both residents and staff physicians. “They had not looked at the super-utilizer population before we posed the question,” says White.

Many of the physicians were part-timers or residents who weren’t particularly qualified to handle complex patients and often didn’t know their patients had been admitted to the hospital until three or four days later.

“Six of [our patients] have had residents for their primary care, and three of them had first-year residents. These are people right out of medical school. When you think of the complexity of these patients … We feel we have a lot to offer, but the system is not set up to give these patients the level of care they need.”

Brenner says that with their fragmentation, and high turnover of staff, the big academic medical centers will be the last ones to the table.

The savings are clear: more than $100,000 in costs cut since Maine General Hospital started the program with 30 frequent ED users in 2011. The biggest challenge is figuring out how to share patients’ data while respecting privacy and confidentiality within the Health Insurance Portability and Accountability Act (HIPAA) standards.

“That pilot project clearly demonstrated that there is success and value in this effort,” she says. “It’s clear to me we’ve got to have that kind of unit within the Medicaid program.”

Laura Putre is a freelance writer whose work has appeared in The Oprah Magazine, Hospitals & Health Networks, Cleveland Clinic Magazine, Today’s Hospitalist and other national publications. She is also the editor of Bel, a new online magazine “devoted to long-form journalism, essay, and commentary with a distinctly Rust Belt sensibility.” She lives in Cleveland.

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“Smaller settings, because they are already flatter and more relationship-centric, will be able to figure this work out.”

SCALING UP: THE NEXT BIG CHALLENGE

The hope is that this super-utilizer work can be applied on a grander scale, with more and bigger payers for coordinated care.

During the Super-Utilizer Summit, Stephen Cha, MD, chief medical officer at the Center for Medicaid and CHIP Services, identified four key policy decisions for state Medicaid officials:

• Should we pursue a super-utilizer program?
• What payers are involved?
• Who provides the services and what is their relationship to primary care providers? What is the targeting strategy?
• How is the program funded?

Medicaid support for care models includes waivers; targeted case management; medical homes; and integrated care models.

“We’re ready to partner with states,” says Cha, “but don’t come in and tell us what authority you want, tell us what you want to do for your population, for your state.”

Mary Mayhew, commissioner for the Maine Department of Health, says she is following the Kennebec Valley pilot project closely to see how it might work at the state level.

The hope is that this super-utilizer work will be able to figure this work out.”