FACING FENTANYL

A new reality for WORKFORCE TRAINING

MEDICAL GUIDELINES, from the patient’s perspective

VIOLENT EXTREMISM hits home

CAN PUBLIC POLICY SLOW THE Trajectory of the Most Dangerous Illegal Drug in America? PAGE 4
Drones for Blood Delivery
Autonomous unmanned aerial vehicles may be an effective way to deliver blood that helps save the lives of U.S. military personnel, getting blood to difficult-to-access areas faster and helping to bolster the military’s blood supply network. A recent RAND report examines key considerations about this emerging form of blood transport—including questions about cost, efficiency, delivery times, and the effect of extreme temperatures on blood quality.

MORE AT www.rand.org/t/RR3047

Putting Data to Work for Young People
Expanded learning intermediaries are dedicated to making after-school and summer programs better and more accessible for children and youth within their communities. This ten-step plan offers practical, research-based advice to those in the expanded learning field who work with data, or want to work with data, particularly intermediary staff with experience in data selection, collection, and management.

MORE AT www.rand.org/t/TL350

Economic Experiments for Global Impact
Implementing effective solutions for global socioeconomic development and poverty alleviation is a daunting challenge. However, RAND has seen over its decades of work in this area that data-based decisions can improve the welfare of the world’s most vulnerable populations.

MORE AT www.rand.org/b191023kumar

The Policy Currents Podcast
Policy Currents is RAND’s weekly five-minute podcast, which highlights the organization’s new research findings, commentary, multimedia, and events.

MORE AT www.rand.org/podcast

Scientific Evidence on the Effects of State Gun Laws
In September 2019, senior behavioral scientist Andrew Morral presented testimony before the Pennsylvania State Senate Judiciary Committee. Morral is director of the philanthropically funded National Collaborative on Gun Violence Research and leads RAND’s Gun Policy in America initiative.

MORE AT www.rand.org/t/CT518
The danger at home

Colin P. Clarke on what a deadly shooting at a Pittsburgh synagogue says about the threat of violent extremism in America

Poisoning Outbreak

The fentanyl crisis demands a new approach

Work in the Information Age

Learning to compete in the 21st century

Patient-Centered Health Care

Giving patients a voice in medical guidelines

Giving

A $2.5 million gift to expand RAND’s impact

Infographic

Improving jobs and trade in the Levant
I study terrorism. A white supremacist attack in my neighborhood woke me up to dangers at home.

By Colin P. Clarke

It took an attack on a Jewish synagogue in my Pittsburgh neighborhood to wake me up to the dangers of violent white supremacy. And I’m a terrorism researcher who studies and analyzes the how and why of politically and ideologically motivated violence.

Yet because I focused on Salafi jihadists, groups in the Muslim world that believe in a return to “pure” Islam and the use of violence to make this happen, I failed to recognize the extremists in my midst—those who praise Hitler and speak openly on social media of hatred for Jewish people.

On October 27, 2018, I was home with my two young daughters when I began receiving a flurry of confusing text messages asking if we were safe. I turned on the television to see breaking news reports on a multiple-casualty shooting at the Tree of Life synagogue, barely a mile from my house in Squirrel Hill, the quiet community where I’d lived for a decade.
Hearing a wail of sirens, I looked out a window and saw an armored personnel carrier racing down my street. A shelter-in-place order was issued as rumors spread that the heavily armed gunman (or gunmen, they didn’t yet know) was on the loose. These rumors later proved untrue—but in the moment, they were terrifying. I locked the doors to the house and took my kids into the basement. While I anxiously cradled my 3-month-old, I tried to persuade my 3-year-old that we were playing a game by hiding.

As I attempted to sort fact from fiction—something I’d done dozens of times as a terrorism researcher piecing together incidents as they unfolded around the world—it struck me that I’d been guilty of viewing terrorism as happening “out there,” in Yemen or Somalia. Now it had struck incredibly close to home: The gunman, motivated by virulent anti-Semitism, killed 11 worshipers and injured seven inside the synagogue.

As a college senior, I had been so affected by the 9/11 attacks that I decided to forgo a potential career in law or finance and dedicate my professional life to researching terrorism. Now I teach courses on terrorism to Carnegie Mellon University students, few of whom remember a world before 9/11. To them, 9/11 and al-Qaida’s attack on New York and Washington is history. I tell them how that history changed the course of my life.

Terrorist attacks on American soil today, however, are often committed by Americans targeting other Americans. The instances of domestic terrorism today are up significantly from a decade ago, as outlined by the University of Maryland’s global terrorism database.

The warning signs were there. But many terrorism researchers, including me, remained fixated on analyzing terrorism that occurred overseas. Even when I began to mentally process the attack in Pittsburgh, I—like many others—figured that the perpetrator had probably been radicalized by jihadist ideology, most likely inspired by Islamic State in Iraq and Syria. The group’s propaganda had long urged individuals in the West to carry out attacks. Homegrown terror attacks linked to Islamic State had occurred in San Bernardino, Calif., in December 2015 and again in Orlando, Fla., the following June.

The threat of white supremacy is now impossible to ignore. Since 9/11, more people have died in the United States because of white supremacist terrorism than jihadist terrorism. The tragic tipping point was the August attack that killed 22 mostly Latino victims in El Paso.

Just in 2018, white supremacy extremists were connected to 50 murders, including those at the Tree of Life synagogue. White supremacists killed more people last year than at any point since 1995, the year Timothy McVeigh bombed the federal building in Oklahoma City, killing 168 people.

Since the Tree of Life attack, the conversation surrounding white supremacy has grown louder. There have been hearings on the topic of white supremacy and domestic terrorism on Capitol Hill, for instance. The Department of Homeland Security also recently released a counterterrorism strategy that puts the threat posed by white supremacy extremists on par with those potentially emanating from jihadist terrorists.

The United States still has a long way to go in dealing with this threat, however. President Trump’s rhetoric is often counterproductive. After an avowed white supremacist drove his car into a crowd of counterprotesters at a “Unite the Right” rally in 2017 in Charlottesville, Va., Trump said “there’s very fine people on both sides.” The president’s recent references to the possibility of “civil war” if he is removed from office could be misinterpreted by white supremacists as a call to participate in a race war, which plays into long-held conspiratorial prophecies in the movement.

Bills have been proposed in the House and the Senate, but most focus solely on domestic terrorism. Many white supremacy extremists operating in the United States have connections overseas, including ties to neo-Nazis in Ukraine, and focusing only on domestic terrorism is unlikely to adequately address this threat.

The United States could consider designating such transnational white supremacy extremist groups as foreign terrorist organizations—a move already taken by our allies Canada and Britain. Terrorist designations by the departments of State and Treasury would deny members of these white supremacy groups entry into the U.S., block assets of those individuals and groups, and allow the Department of Justice to prosecute anyone providing them with material support.

Pittsburgh is still reeling, but it has rallied around Squirrel Hill’s Jewish community in the last year, and the feeling is one of resolve, not despair. The message the city sends is also a poignant one, displayed prominently on T-shirts and signs that dot front lawns and hang in the windows all over town. They showcase a Star of David set into the Pittsburgh Steelers logo and three powerful words: Stronger Than Hate.

As for me, it shouldn’t have taken an act of terrorism near my home for me to realize I needed to broaden my research to look more closely at the threat of extremist violence in my own country. But it did.
Poisoning Outbreak

America’s fentanyl crisis is unlike previous drug epidemics. Solving it requires innovative approaches and unprecedented resources.
Drug overdoses kill more Americans than car crashes, gunshots, or AIDS at its peak. But it’s no longer just a crisis of prescription pills or heroin. It’s a crisis of fentanyl. Deaths involving it and other synthetic opioids have surged from around 3,000 in 2013 to more than 30,000 in 2018.

Researchers at RAND recently published the most comprehensive study to date on what’s driving the crisis, how it could play out in the future, and what may be done to save more lives. Among their findings:

• Fentanyl is unlike any other drug problem in modern history. It’s more useful to think of it as a mass poisoning than as a traditional drug epidemic.

• The crisis is likely to get worse. Fentanyl and other synthetic opioids have swept through some parts of the country while leaving others almost untouched. There are signs that’s changing.

• Confronting the crisis is going to take more than disrupting the supply and getting people into treatment. Innovative, and controversial, responses—such as supervised drug-consumption sites and fentanyl test strips—must be part of the policy discussion.

“This is a new era,” said Bryce Pardo, the lead author of the new report and an associate policy researcher at RAND who specializes in drug policy. “We haven’t seen anything like this since heroin first hit the streets more than 100 years ago.”

Source: Data for this figure are from deidentified MCOD certificate files produced by the National Center for Health Statistics, 2005–2017, shared with RAND researchers under a data use agreement. Note: The rates for 2018 are provisional and subject to change.
Lethal, and easy to obtain

The crisis arrived in Dayton, Ohio, with a series of unexplained deaths in the fall of 2012. Police found a white powder that looked like heroin but tested positive for fentanyl. By 2015, as the crisis took hold, more than 250 people were dying of drug overdoses every year in Dayton and the rest of Ohio’s Montgomery County. The death toll rose to nearly 350 in 2016. The year after that: 566. The coroner’s office had to bring in refrigerated trucks to accommodate the dead.

“It was terrifying,” said Ann Stevens, who helped coordinate the response for the county’s Alcohol, Drug Addiction, and Mental Health Services agency. “These were people next door, friends and family. The effects just rippled through the community. Everybody knew somebody.”

Fentanyl is not a new drug. It’s been used for decades as a painkiller and anesthetic. Surgeons learned to watch their patients closely after administering fentanyl because of the way it stiffens the muscles that control breathing. It was hard to make and hard to find on the streets—until it wasn’t.

Today, fentanyl is a mail-order product, marketed on the open internet and shipped directly to consumers and dealers, no international drug cartels required. Some of it comes across the border from Mexico, but much of it comes from poorly regulated labs in China. They often guarantee delivery, so sure are they that their small packages will slip by in cargo shipments or standard mail.

RAND researchers found several Chinese firms willing to ship a kilogram of nearly pure fentanyl to the United States for as little as $2,000. A shipment of heroin with the same potency would cost at least 50 times that much.

Drug dealers didn’t need much imagination to see that they could cut a bag of heroin with cheap fentanyl and pocket the difference. But fentanyl is not just cheaper than heroin; it’s also up to 30 times more powerful, and some of its chemical cousins are even more potent. A dosing error equivalent to a few grains of salt will kill a person. Users wouldn’t even know what was hitting them until it was too late.

A geographic rift

Lori Erion heard a new note of fear in the voices of fellow parents as fentanyl started coursing through Dayton. At the support group she runs, Families of Addicts, people shared the names of people lost and worried their children would be next. She felt the fear herself. Her daughter, April, a longtime heroin user, told her there was no such thing as plain heroin anymore. It was all fentanyl.

“I would go to bed at night praying, God, do with her what your will is,” Erion said. “If it’s to take her, because she’s never going to get better, then take her. But if it’s not, protect her, save her, help her. Because every night I lay there wondering whether I would get the call.”
Ohio was in the eye of the storm. But synthetic opioids were also flooding into New England, Appalachia, and some Middle Atlantic states. By 2016, they had pushed aside heroin, cocaine, and prescription opioids to become the most dangerous illegal drugs in America. Yet RAND’s research highlighted a geographic rift: At least through 2017, fentanyl and other synthetic opioids had not yet become nearly the killers west of the Mississippi that they are in the east.

That might be because East Coast drug users favor white-powder heroin, which mixes easily with powdered synthetics (one common mixture is known as “gray death” on the streets). West Coast users prefer their heroin in tar form. But drug dealers are starting to get creative, pressing fentanyl into counterfeit pills. And there’s some evidence from Ohio indicating that 12 percent of retail-level cocaine samples obtained by law enforcement also included fentanyl.

Those trends suggest synthetic opioids could still surge into the west, researchers warned—and become even more lethal. Users who think they’re getting cocaine or medical-grade pills probably won’t have the opioid tolerance of someone who regularly uses heroin. And a pill manufactured in a garage press could have a small amount of fentanyl in it, or enough to kill someone several times over. “The margin of error is so narrow,” RAND’s Pardo said. “One more milligram, and that could put you in the grave.”

With fentanyl, traditional interventions do not suffice

Randall Carmack parked his car on a recent morning at the edge of a field near downtown Dayton. He trudged a short distance to a broken-down car covered with old blankets and towels, to check on a heroin user he was hoping to get into treatment. He found the man slumped in the front seat, his face turning blue.

Carmack sprinted back to his car and grabbed his supply of naloxone, a drug that can reverse an opioid overdose and restore breathing. He ran back and administered it, but at first nothing happened. He tried again. The man gasped. His eyes opened.

“There’s really no other drugs around here that make people do that,” said Carmack, who once used drugs himself, including medical-grade fentanyl. He’s now eight years in recovery and working as a peer support specialist for the county’s public health department.

“There’s no heroin on the streets of Dayton anymore,” he added. “It’s very, very rare that it’s heroin anymore. Everybody wants fentanyl.”

RAND researchers interviewed experts, public health officials, and drug-enforcement agents in half a dozen countries. They found not a single instance where fentanyl had become entrenched and then been pushed aside. Estonia has had an illicit fentanyl market for nearly 20 years.

Against those odds, they wrote, the United States must invest more in getting people with substance-use disorders the treatment they
need. It must find ways to interrupt the flow of synthetic opioids through the mail, and make naloxone much more readily available to those who need it. But none of that will be enough.

At least 10 countries have implemented supervised-consumption sites, where people using drugs at least have trained staffers watching over them in case they overdose. A recent court ruling in Philadelphia suggested there may be a legal pathway to try that approach here. Some countries also allow doctors to prescribe medical-grade heroin to those who have tried other treatments, such as methadone, multiple times but are still injecting heroin. Researchers found good evidence that the approach can reduce the use of illicit, contaminated heroin and stabilize the lives of those patients.

Decisionmakers need to consider such outside-the-box ideas if they want to significantly reduce deaths involving synthetic opioids, RAND’s study concluded. “Just because something is controversial doesn’t mean we shouldn’t consider it,” said Beau Kilmer, the director of the RAND Drug Policy Research Center and a coauthor of the new study. “We can’t treat this like a regular drug epidemic.”

‘Mobilize as quickly as possible’

In Dayton, as drug overdoses mounted, the community pulled together. Neighbors, business leaders, and community groups formed an emergency action team to track and respond to the crisis in real time. The health department offered free training for anyone to

“Just because something is controversial doesn’t mean we shouldn’t consider it. We can’t treat this like a regular drug epidemic.”

BEAU KILMER

ABOUT THE RAND DRUG POLICY RESEARCH CENTER

The RAND Drug Policy Research Center just celebrated its 30th anniversary.

When it was founded in 1989, U.S. concern about illicit drugs had risen to near-panic levels. Violent crime, much of it related to drug distribution, was in the midst of a historic run-up, and media reports of “crack babies” contributed to a sense of cities spinning out of control.

Public opinion polls showed that drugs were seen as the most
learn to use naloxone, every Wednesday at noon. Clinics handed out test strips so that drug users could check their drugs for fentanyl.

It’s hard to say what made the difference—the community response, the naloxone, or just changing patterns of drug use or supply. By 2018, overdose deaths had fallen by nearly half, from 566 to 289. Early numbers from 2019 suggest they were holding steady. But the community itself is still in recovery.

Lori Erion almost lost her daughter, April, to the crisis; she overdosed one night in an abandoned house and was brought back by naloxone. “That’s what families go through,” Erion said. “It’s a horrible, horrible thing.” Randall Carmack spends his days knocking on doors, offering people with substance-use disorders a shot at treatment in the language of someone who’s been there himself. “We still get at least one [overdose] a day,” he said. “That’s the bare minimum.”

And Ann Stevens, whose agency helped rally the community response to the crisis, has some advice for communities in fentanyl’s path: “Mobilize as quickly as possible. Get everybody to the table. Every community in the country needs to see this as a public health crisis.”

The overdose numbers are down in Dayton. National news headlines don’t point to the city anymore as an epicenter of the nation’s drug epidemic. But Stevens still keeps a dose of naloxone in her purse, just in case.
As vice president and director of RAND Education and Labor, V. Darleen Opfer oversees a research portfolio that ranges from early childhood education to retirement planning. The research division’s goal is to make students and workers more effective in the ever-changing, ever-innovating world of the 21st century. Opfer’s research has helped school districts, states, and countries from Great Britain to India to Mexico improve teacher training and student outcomes. She also has served as an education consultant for the U.S. Agency for International Development and as a fellow for the Organisation for Economic Co-operation and Development. She began her career in the classroom, as a special education teacher, before moving to policy research.
Q Let’s start with the perennial question: What should we be doing to improve education?

A We need to use more evidence-based practices. We’ve got a history in the field of implementing ideas or programs or policies because they’re popular or because people think they sound like a good idea. But often, we have no evidence that they’re going to work. So people go from an idea to full scale-up without ever seeing if it’s going to work the way they intend it to. That’s something we really need to change.

Were there any experiences in your time as a classroom teacher that inspire the work you do now?

Absolutely. I became a teacher because I wanted to help students—particularly low-income students—succeed. I taught for three years, and it very quickly became obvious that we make bad decisions for kids. As a special ed teacher, there were a lot of rules and regulations that you had to follow, over and above what other teachers did, and I was constantly questioning, ‘Why would we do it this way? Does this even make sense for these students?’ That led me to go back to graduate school and earn my Ph.D. in education policy. I wanted to make sure we were making better decisions for students, more evidence-based decisions, that would lead to better results for them.

You’ve worked on education issues all over the world. Are there any lessons or ideas that we should be looking at here?

You hear that question all the time. People will start looking at Finland, for example, and ask, ‘What is Finland doing and how can we implement it here?’ But it can actually be dangerous in education to take ideas from one country and apply them to another. Context really matters and there are lots of cultural differences between countries, even those that speak the same language.

I’m doing a study right now with eight countries, looking at the relationship between math teaching and student outcomes. And it’s just striking, even with something as narrow as middle school math, the difference between what—and how—they teach.

Your research division covers not just education but also labor. Why group those two fields together?

There’s a growing realization that we need to make some radical changes if we’re going to prepare people for work in the future. There’s been a lot of talk about it among policymakers, among the general public, certainly among employers. We understand this as a large, systemic problem. It’s not something we can fix by just tinkering around the margins, implementing new programs in schools, that kind of thing. We need to have labor researchers working together with education researchers, to be able to think at that system level about the improvements that need to be made.

What do you see as the top priorities right now?

We’re really digging in on the labor market and how it’s changing and evolving. And it’s become apparent that there are issues we need to address in how we train our workforce in response to those changes. One of the big problems we see is that people go through school, they finish high school or college, and then they go out into the workforce. They never re-educate themselves. And what we’re seeing even now is that people need to learn new things, new skills, throughout their working lives to stay competitive in the labor market. They really need to think of learning as a lifelong process, not as something that’s done when they graduate. That’s not something we’ve been very good at in the United States.

What’s next for you on the research side?

Most of my work focuses on helping teachers better educate their students. I’m working on a project to look at what we’re calling ‘coherent instructional systems,’ and whether they make a difference for low-income students. Our hypothesis is that one reason low-income students often struggle is because they’re in systems that are incoherent. By that, I mean the curriculum doesn’t align with the assessments, or the professional development that teachers are participating in really has nothing to do with the curriculum. We’re trying to identify schools and school districts where there is alignment among all of these instructional elements. We want to see whether that really does lead to better outcomes.
It’s 2020, but too many American workers still aren’t getting the education and training they need to compete in the 21st century. Something’s not working here, and it’s not just the few million people struggling to find jobs.

A new RAND report argues it’s our entire system of educating and employing people, from their first day at school to their last day on the job. We are preparing workers for a labor market that no longer exists, researchers concluded, and then sending them flat-footed into a world of dizzying change.

What would it take to fix that? To answer that question, the researchers asked another: What if we just scrapped everything and started over? What would we want the American education and labor system to look like if we built it from scratch?
A good education, reformer John Dewey once proposed, is one that helps young people develop “in an orderly, sequential way into members of society.” He was writing in 1934, but that’s still a pretty good description of how we prepare the next generation for work and for life. It’s orderly. It’s sequential. You go to school, you get a job, you retire. But the world doesn’t work that way anymore.

“Things are changing so rapidly that we can’t necessarily prepare people for the jobs they’re going to be doing in 20 years,” said Lynn Karoly, a senior economist at RAND who coauthored the new report. “We don’t really even know what things are going to look like in five years.”

A recent survey found that two-thirds of employers do not think people are graduating with the skills they need to make it in the 21st-century labor market. It’s not enough anymore to ace reading and math; employers want to see teamwork, communication, an ability to take information and do something new with it. They want workers committed to keeping up with the ever-changing demands of the workforce.

That means education does not stop with a diploma. Workers in all industries need to become lifelong learners—and employers, educators, and policymakers need to accommodate that new reality. The system needs to work less like a career ladder, with workers climbing rung after rung, and more like a freeway, with offramps for workers to refresh their skills, earn new certificates or credentials, and then merge back in.

There are places where that is happening already. In the coal counties of Appalachia, for example, community colleges have teamed up with employers to help workers retool for the burgeoning natural-gas industry. Germany offers its workers education savings accounts that they can use to pay for continuing education.

“The key takeaway from our report is that there isn’t any one single pathway anymore,” said Melanie Zaber, the lead author and an associate economist at RAND. “We need to find ways to support workers on a multitude of pathways.”

Technology is often cast as the great disruptor in this kind of future workforce planning. One recent poll, for example, found that nearly 20 percent of workers doubt their jobs will even exist in 20 years. Another study tried to identify jobs that will be least susceptible to computerization (think recreational therapists and elementary school teachers) and most susceptible (insurance underwriters, sports referees, and, at the top of the list, telemarketers).

But technology is as much a part of the solution as the problem. Better use of online learning and digital credentials would give workers more opportunities to keep their skills current. Greater acceptance of telecommuting would keep some people, such as older workers, in the workforce longer, and help others match their skills to jobs, no matter how distant.

But beyond that, a workforce training system for the 21st century needs to be built on data. We should be tracking workforce demand in real time, forecasting when and where skills will be needed in the near future, and communicating that to educators and workers. Employers should not find themselves with jobs to fill and too few qualified candidates. Students and workers should not have to plan their futures with incomplete or outdated information about what their future prospects look like.

One way to accomplish that is with an electronic training record, the researchers wrote—a searchable resume, updated in real time, of a worker’s education, skills, credentials, and work history. There are obvious privacy concerns here, and federal law flatly prohibits tracking some education details like that. But done right, such records would allow workers and employers alike to better match qualifications to job openings.

“We need to experiment with new ideas, see what works and what doesn’t, to help us move toward the transformation that’s needed,” Karoly said. “There’s some inertia in the system. It worked for an era, but now we need to revamp.”

To stay competitive on the shifting grounds of the 21st century, that system needs to make sure people have equitable access to opportunities and learning throughout their working lives. It needs to do a better job of matching and rematching skilled workers with open jobs. And it needs to recognize that education and employment are no longer two separate arenas, but two parts of the same whole.

“We need to really think about this differently,” said V. Darleen Opfer, vice president and director of RAND Education and Labor. “The way people talk about this is as if education is one system and the labor market is another. We need to think about this as one system, education and the labor market working together, not separately.”

For workers, the payoff from that shift in thinking could extend well beyond the hours of 9 and 5. A good job has been found to be as important as good health in predicting someone’s quality of life.
Patient-Centered Health Care

Health Care Professionals Aren’t the Only Experts

By Doug Irving, Staff Writer

A FOCUS ON THE RESEARCH OF
Dmitry Khodyakov, Sean Grant, Brian Denger, Kathi Kinnett, Ann Martin, Marika Booth, Courtney Armstrong, Emily Dao, Christine Chen, Ian D. Coulter, Holly Peay, Glen Hazlewood, and Natalie Street
Brian Denger knows as much as anyone about caring for a child with Duchenne muscular dystrophy, a rare and fatal genetic disease. But you won’t find him listed as a contributor to the clinical guidelines that doctors use to treat the disease. That’s because he’s not a medical expert, not a doctor; he’s a father.

Clinical guidelines have become as much a part of medicine as lab coats and stethoscopes. They can dictate insurance coverage and help hospitals set quality standards. Yet they often lack the perspective of people like Denger who care the most about good treatment: patients and their caregivers.

Researchers at RAND have been working with Denger and other families living with Duchenne to better center clinical guidelines on the realities of real patients and caregivers. Their solution borrows from a method developed at RAND nearly 70 years ago to help military planners think through the challenges of the emerging Cold War, the Delphi method.
The experience of patients and caregivers

Denger bought his son Matthew a tricycle for his fourth birthday. Matthew couldn’t seem to pedal it. He sometimes stumbled when he walked, despite what appeared to be especially well-developed calf muscles. All of those, Denger now knows, are signs of Duchenne.

The disease, a single glitch in the genetic code, affects almost exclusively boys and attacks the major muscles in their bodies. Matthew couldn’t walk by the time he was 8. He couldn’t roll himself over in bed when he was 13. “What’s your job?” his father would ask him. “To call you,” was the answer. “What’s my job?” “To come help me.” Matthew died of heart failure when he was 20.

Denger has the same deal now with his younger son, Patrick, who also has the disease. He’s become a veteran of daylong doctor visits, an expert at lifting his son onto an exam table and positioning him to be comfortable during a bone scan. He signed on to RAND’s project to make sure the guidelines for treating patients like his two sons take into account their experiences.

“What may seem to be an otherwise easy protocol for treatment might not be for all people,” he said. “It may not change any decisions, but the doctor might be able to provide more guidance in certain areas, to help families anticipate potential pitfalls.”

Clinical practice guidelines are the user manuals of modern medicine. If the human body can suffer it, chances are there’s a guideline for treating it, from burns and breaks to cancers and strokes. At their best, they provide gold-standard guidance to doctors: how to diagnose and treat a condition, what symptoms to watch for, what tests to order.

But that’s not always the reality. The National Academy of Medicine has described guideline development as “unsatisfactory and unreliable.” In part, that’s because it so often fails to engage any patients or caregivers. One study found that three-quarters of clinical guidelines were developed without any input from the people who would actually experience them.

“It’s patients who have to follow these clinical recommendations,” said Dmitry Khodyakov, a senior sociologist at RAND who has worked for years to solve that problem. “Clinicians can recommend something, but at the end of the day, they don’t have much power over whether or not a patient will actually take the pill or do the test. If we can understand what the barriers and concerns are for patients, we can write better guidelines that they’re more likely to follow.”

Which brings this story back to 1951.

Building a better guideline

RAND researchers wanted to know how many nuclear bombs it would take for the Soviet Union to cripple America’s munitions industry. They asked several experts for their best estimates. Then they sent those answers around to the group and asked the experts to reconsider their estimates in light of how everyone else had answered. Over a few rounds of that, the estimates converged around a single, consensus answer. (In the bombing question, it was around 275.)

That approach has come to be known as the Delphi method, after the classified project it was part of. It’s been adapted and expanded for use in business and police work, engineering, and health care. A version of it, developed by RAND and UCLA, has become the industry standard for developing clinical guidelines, to make sure they reflect the consensus of medical experts. Khodyakov thought
it could give patients a meaningful voice in those guidelines, too.

He teamed up with Parent Project Muscular Dystrophy (PPMD), an advocacy group that maintains a national registry of Duchenne patients. From that, the study team recruited more than 100 people living with Duchenne as patients or caregivers. They reviewed more than a dozen recommendations in the existing guidelines for Duchenne, rating them on their importance and their acceptability. Then they discussed their ratings in an online forum, and revised their ratings in light of that.

In the end, they agreed that most of the recommendations were both important and acceptable—but with some extra considerations. They pointed out that patients with Duchenne might not be able to lie flat for long periods of time for recommended bone scans. They questioned whether children should be expected to undergo some treatments that require regular injections. They disagreed, even within the group, over how important it is to treat puberty delays in boys with Duchenne. And they wanted to know whether insurance would cover everything the guidelines prescribed.

The results didn’t overturn any of the existing recommendations; that wasn’t the purpose. Rather, they revealed some nuances that could make future versions more useful to doctors—and more likely to be followed by patients. The team called its approach the RAND/PPMD Patient-Centeredness Method.

“We haven’t had a good method for involving patients before. That’s where I think this method is really powerful,” said Natalie Street, a health scientist and genetic counselor at the Centers for Disease Control and Prevention, who helped develop the Duchenne guidelines. “Clinicians are experts, but the patients with the disease are also experts. They’re the ones living with it on a daily basis.”

Khodyakov has met with groups working on guidelines for other diseases to describe the method and the importance of getting patients involved. Duchenne was a good test case, he said, because the disease is so rare, so complex, and the balance between treatment and quality of life is so precarious. But there’s no reason the method couldn’t work for any disease.

That would help make clinical guidelines a little less clinical, and a little more responsive to patient preferences, concerns, and values.

“If Frankly think it’s a little bit silly to develop guidelines without engaging patients and their families,” said Kathi Kinnett, a nurse practitioner and the director of the Certified Duchenne Care Center Program. “So many times in the hospital, we make recommendations and then are surprised when patients come back and haven’t followed them.”

Brian Denger sees one other important lesson here. Guidelines may describe a typical patient; but for patients and caregivers, there’s no such thing. His son Matthew died of complications from Duchenne at 20; his other son, Patrick, with the same disease, recently turned 25. He can’t walk, but he can drive. He’s a college graduate, an occasional pianist, and a professional gamer with an online following and a dominant record in “The Legend of Zelda.”

“It’s important to get the patient voice in there,” Patrick said. “We’re living with it; we know what goes on. Even with this condition, you can still lead a pretty normal life. I can drive, I have friends, I have all the stuff that everyday people have.”

Clinical guidelines can provide the best recommendations, the most up-to-date treatments and tests, his father said—but that’s not everything in patient care. “It’s that human aspect, or course, that’s the hardest part,” he said.

DMITRY KHODYAKOV

The RAND/PPMD Patient-Centeredness Method: A Novel Online Approach to Engaging Patients and Their Representatives in Guideline Development is available for download at www.rand.org/t/EP68014.

Using an Online Modified-Delphi Approach to Engage Patients and Caregivers in Determining the Patient-Centeredness of Duchenne Muscular Dystrophy Care Considerations is available for download at www.rand.org/t/EP68015.
By Melissa Bauman, Staff Writer

At RAND, tattoos sometimes reflect the research

SEMPER FI. Like many Marines, policy researcher Jonathan Wong got a tattoo right out of basic training. The bar code on his forearm that says 0311USMC (311 was his unit’s job code) memorialized his sense of pride in being a Marine but also his “smallness in the vast scheme of things.” As a researcher, the tattoo has taken on new meaning. “One of the reasons I was interested in working at RAND was because I wanted to continue to help examine all the problems the Marines face,” he said. “It’s a reminder that the work that I do will impact people in positions like I used to be in.”

PHOTOGRAPHY BY DIANE BALDWIN/RAND PHOTOGRAPHY
A LOVE OF LABOR. The vintage Soviet postage stamp shows a steel worker and the Russian word for “labor.” To demographer Robert Bozick, his stamp tattoo represents both his background and his research. A native of industrial Youngstown, Ohio, Bozick grew up among blue-collar laborers and is the first in his family to attend college. It’s why his research focuses on changing demographics and changing needs of the labor force. “I wanted something that could visually remind me of my roots and why I started doing what I was doing regardless of where my career took me.”

A MOVING TARGET. “Where are you from?” is a tricky question for Hardika Dayalani, a doctoral candidate at the Pardee RAND Graduate School. “What is really being asked is ‘Where do you belong?’” she says. The list of airport codes down her spine “represents all the cities that I feel a sense of belonging for and all the cities I feel homesick for.” While the tattoo preceded her research, “my work has the same inspiration.” She began studying migration-related issues after working at a nonprofit that helped refugees. “Migrants carry their home with them on their backs,” she said. “Home is where the heart is, but you carry your home with you.”

CONVERSATION STOPPER—AND STARTER. Death might seem like odd cocktail conversation. But when people ask policy researcher Sangeeta Ahluwalia about her phoenix tattoo—symbolizing life, death, and rebirth—she jumps at the chance to chat about her research into end-of-life care. “As many times as there’s that pregnant pause, there’s just as many times when someone will relate their story,” Ahluwalia said. It’s a conversation worth having because society’s approach to death and fear of death make end-of-life care especially challenging, she said. “That’s something that could be avoided if we thought about it differently.”
Giving

Former Labor Secretary Ann Korologos, a longtime supporter of RAND, has pledged $2.5 million to extend the reach and impact of its research.

It’s a gift in support of what she calls “pure research,” unflinching and unmoved by the politics of the day.

“Being close to the government at senior levels, you can’t help but be grateful there’s a RAND,” she said. “I wish the United States Congress would call RAND even more often and say, ‘We’re thinking about developing some legislation on such-and-such, to solve a problem for the American people. Do you have any ideas?’”

Korologos served as labor secretary under President Reagan from 1987 to 1989. She focused on improving the representation of women and minorities in the workforce, and pushed for tax credits to help working families afford child care. She made headlines by predicting that jobs would be plentiful in the early 21st century, but workers might not have the right skills or education to compete for them. That same idea has become a focal point of RAND research.

Korologos previously had served as under secretary of the Department of the Interior. She went on to chair the President’s Commission on Aviation Security and Terrorism, and to lead the nonprofit Federal City Council in Washington, D.C. She also has served on the boards of several Fortune 500 companies, including Microsoft, Kellogg Company, and the parent corporation of American Airlines.

She’s currently chairman emeritus of the Aspen Institute, an organization that brings together thinkers and leaders to confront some of the world’s most pressing problems. She’s also an avid art collector and owns the Ann Korologos Gallery outside of Aspen, Colorado.

She’s been a part of RAND for more than 20 years, as a leader and as a donor. She has served on the Board of Trustees since 1996, with a short break in 2010, and chaired it for five of those years. “The idea of going where people know what they’re talking about struck me as pretty good, especially after experiencing the world of Washington punditry,” she said. “I’m always smarter when I leave a board meeting at RAND than when I came in.”

Several years ago, for example, RAND published a report on how the military could more efficiently move equipment. Korologos was serving at the time on the board of Vulcan Materials, the nation’s largest producer of sand and gravel. The ideas in the report, she realized, could apply just as well to moving huge quantities of crushed rock.

She’s shared RAND research on rebuilding Puerto Rico with friends working on the island. She drew on RAND research on the Middle East when she became chair of the Middle East Investment Initiative. And she sent a RAND report on the efficacy of chiropractic treatments to her son-in-law, a chiropractor in Virginia.

“RAND research is all so relevant,” she said. “It’s not something that’s just going to go into the bottom left-hand drawer of someone’s desk. It goes into so many sectors of society that are so important.”

She established the Ann Korologos Endowed Scholarship for students at Pardee RAND Graduate School in 2012. Her most recent gift includes $500,000 to support the school as it reimagines public policy education to better meet the needs of the 21st century.

And a recent $2 million estate gift has established the Ann Korologos Impact Award Endowment. RAND will award funds from the endowment to help researchers build on especially important and timely studies, expand their impact, and make sure they get into the hands of those who need it.

“My hope is that it will support something that no one else has thought of,” Korologos said, “something that is life-changing in some way, whatever that means—life-changing for our country, life-changing for a policy area.”

“I give to other organizations, but there are precious few that you think will be around in 50 years, even 10 years, still having an impact, still being the answer to some problem,” she added. “That’s what’s special about RAND.”

To learn more about giving, visit www.rand.org/giving
Q: What if six of the core Levant countries developed a comprehensive free trade agreement?

A comprehensive free trade agreement that eliminates tariffs, lowers investment and nontariff barriers, and waives visa requirements would create substantial gains, driving economic growth and creating potentially millions of new employment opportunities. Although maximum benefits assume some degree of stabilization of the Syrian and, eventually, Israeli-Palestinian conflicts, the potential gains from even partial integration (such as the recently penned Iraq-Jordan economic agreements) could be the start of a potential takeoff for the region.

**Expanded trade** could expand GDP by as much as 3% with new economic opportunities creating as many as **670,000 new jobs**

**New investment activity**—domestic and foreign—could expand GDP by as much as 1.5% with new economic opportunities creating as many as **410,000 new jobs**

**Expanded tourism and travel** could expand GDP by as much as 2% with new economic opportunities creating as many as **570,000 new jobs**

**1.7 million additional new jobs** could be created.

Use the online calculator. Explore the factors driving the benefits of integration at www.rand.org/levant-calculator.

Estimating the Economic Benefits of Levant Integration is available for free download at www.rand.org/t/RR2375.
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