

arrived for a meeting at the US National Institutes of Health to discuss a project to study a condition called pseudoxanthoma elasticum, which affects elastic fibres in some tissues. Even though Terry was the founder of an advocacy group that wanted to fund part of the study, she was told that she could not join the meeting because she wasn't trained in biomedical research. She was eventually allowed to attend, but only if she served as an assistant to the medical director of her group. (Terry decided to pull funding for the project.)

Terry says it is hard to imagine the same scene today. Many pharmaceutical companies and medical centres now routinely consult people with a condition about clinical-trial designs, to get early feedback rather than risk launching a trial that no one wants to join. In response, trial organizers have tweaked protocols and created research programmes. In cancer studies, for example, this type of feedback has fuelled a push to find ways to combat the side effects of cancer treatment, and to improve care for survivors of cancer.

The benefits of such an approach are persuasive. Closer engagement with participants could yield clinical-trial protocols that are more effective and convenient for patients. This can translate into a trial that meets its enrolment targets more quickly, and which has a lower dropout rate.

Nancy Roach, founder of the advocacy group Fight Colorectal Cancer in Springfield, Missouri, recalls a meeting at the US National Cancer Institute about a trial in which participants would be assigned a treatment on the basis of their tumour mutations. An early proposal called for tumour samples to be characterized in three to four weeks. Roach, as well as others at the meeting who represented the participants, said it would not work: the longest they would be willing to wait before settling

on a course of treatment was two weeks. After a subsequent survey of clinicians and investigators confirmed that they would also wait only two weeks before deciding on a treatment, the project team worked with pathologists at the trial sites to shorten the time it took to process the samples. The trial, called NCI-MATCH, initially had trouble meeting those goals because so many more people enrolled in the study than expected. So far, there are more than 6,000 participants.

“It is important to make sure that patient engagement is backed by meaningful action.”

More projects should follow this approach. As the phrase ‘patient engagement’ sweeps through medical science, it is important to make sure that it's backed by meaningful action. It is not enough to put a potential trial participant in the room during meetings to discuss protocol designs. And it's unacceptable that some scientists still consult people about a trial protocol only after it has been approved by a review board, when all involved are reluctant to revise it.

Engagement means offering training to participants and their carers so that they have the skills to contribute with confidence. Some say that it is intimidating to be in a room full of specialists, with the added responsibility of speaking for an entire community of people who have a medical condition. Engagement is also about researchers being willing to incorporate patient feedback. There are plenty of examples of best practice to follow, including lessons from social scientists who have studied community engagement to learn how best to achieve it.

Clinical trials depend on the willingness of participants, some of whom are critically ill. They all deserve a thank you. They rightly expect much more. ■

Welcome change

Science-based policies should benefit from midterm election results in the United States.

US President Donald Trump has taken a wrecking ball to the climate and environment policies of his predecessor, Barack Obama, over the past two years. To some extent, this is to be expected: any administration has the ability and right to lay out its policies and set a new course. But the Trump administration has also shown a complete disregard for the science and evidence that should underpin policy decisions.

In many cases, Republicans in Congress have been all too happy to sit back and watch. The political dynamic will now change, given that Democrats took control of the House of Representatives in the midterm elections last week (see page 302).

As *Nature* went to press, officials were still tallying votes in several close races, but the new balance of power is clear. Democrats have so far picked up 32 seats in the House, giving them a slim but significant majority they can use to block the administration's legislative agenda — just as Republicans did when Obama was president. The Trump administration has often used its executive authorities to advance its agenda independently of Congress, and will surely continue to do so. The difference now is that Democrats will have the power to investigate and raise questions about policies, and to issue subpoenas to compel testimony from reluctant administration officials. This won't necessarily stop the administration, but it will put a public spotlight on the decision-making process. For anybody who cares about evidence-based policies — including this journal — this is good news.

It's a different situation in the Senate, where Republicans will pick up at least two seats. Given the current polarization between Democrats and Republicans, the odds of bipartisan cooperation are slim, but there are some areas in which the two parties might work together. One is the protection of funding for science and science-based

agencies: the current Republican-led Congress has already declined Trump's demands to slash funding for the Environmental Protection Agency (EPA) and other such groups, and there will be little appetite to do so next year. (The long-term budget outlook is bleak, so there might still be plenty of cuts to come.) The other point on which the two parties could unite is spending for research infrastructure.

When it comes to science, all eyes are now on changes to the committees that oversee health and environmental agencies — most notably the EPA, a primary target of Trump's scorn and the main vehicle for his efforts to dismantle rules and regulations that protect the environment and public health but burden industry.

At minimum, expect a change in the language around global warming. The current chair of the House Committee on Science, Space, and Technology, which regularly weighs in on scientific and technical issues, has repeatedly questioned climate science while launching investigations into alleged wrongdoing by scientists and scientific agencies. But Democrat Eddie Bernice Johnson, who is a registered nurse and now the probable future chair of the committee, plans to set the record on climate change straight in hearings next year, starting with an acknowledgement that “it is real”.

As Democrats push back, legal battles will continue to play out in the courts. Republican gains in the Senate will make it even easier for the administration to appoint judges and push the judicial system in a conservative direction. But federal judges have already rejected some of Trump's decisions for lack of scientific analysis. Last week, a federal district court blocked construction of the Keystone XL pipeline, which would help to transport crude oil from the Canadian tar sands to the United States; the court ruled that the administration had “simply discarded” the threat of climate change when approving the pipeline.

Democrats will bring their own agendas. But lately, the party has shown more solidarity with science and evidence-based policymaking.

Come January, when the elected candidates assume their positions, science will have a more prominent place at the political table on Capitol Hill. The United States — and indeed, the world — is facing crucial questions about everything from public health and inequality to global warming. Any development that strengthens the voice of evidence, whatever side of the aisle it comes from, is one to support. ■