1-15 AUGUST, 2020

Down To Earth

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STILL A MYSTERY

Annual tryst with unknown disease outbreaks once again highlights India's defunct health surveillance system

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WHO IS TRACKING INDIA'S HEALTH?

The burden of mysterious ailments mounts in India as its disease surveillance system lies in shambles

VIBHA VARSHNEY

EARLY THIS year, just as governments across the world were scrambling to contain the spread of the novel coronavirus (COVID-19), healthcare practitioners in several rural pockets of India were fighting a similar battle—blindfolded. In Odisha's tribal district of Malkangiri, panic gripped Kenduguda village after over a dozen people died within three months since the end of February. They were all in the age group of 15 to 35 years and complained of acute respiratory problems, fever, swollen legs and bloated stomach. Medical officers from the district hospital, who visited the village in early June, have failed to ascertain the reason behind the deaths and say the deceased could be suffering from either chronic kidney disease, anaemia, tuberculosis or heart ailments. Around the same time, the authorities of Karimganj district in Assam were thrown into confusion after six children in Bazaricherra village died one after the other. Though the reason is not known, media reports say that they had infected tonsils. A similar fear swept through Karnataka's forested district of Dakshina Kannada, infamous for rare illnesses like viral haemorrhagic monkey fever or Kyasanur Forest Disease, in January after the residents of Venoor village complained of prolonged fever with fatigue, pain in the abdomen and headache. Medical officers rushed to Venoor to investigate the illness. Though it could be cured with symptomatic treatment, the authorities are yet to figure out what caused the fever and whether it will strike again.

PHOTO: VIKAS CHOUDHARY / CSE

These unidentified, mysterious diseases are like terrorists with unknown motives and unpredictable moves. They might lead to epidemics, creating a situation worse than COVID-19 where scientists are at least familiar with the pathogen.

India has an elaborate arrangement for early detection of such disease outbreaks under a century-old-institute, now known as the National Centre for Disease Control (NCDC). Surveillance and investigation of communicable diseases have been an integral part of NCDC's activities for close to six decades. Since 1997, after the 1988 cholera outbreak in Delhi and the 1994 outbreak of pneumonic plague in Surat caught the country unprepared, it has a dedicated wing for early detection and systematic reporting of emerging (new) or re-emerging infectious diseases and for timely response. The wing was scaled up in 2012 to fulfil the World Health Organization's (WHO's) International Health Regulations, 2005, that requires each country to assess public health emergencies of international concern within 48 hours and report them to WHO within the next 24 hours. It was renamed Integrated Disease Surveillance Programme (IDSP) and turned into a national health programmes with surveillance committees at the Centre, state as well as district levels; trained rapid response teams and other medical and paramedical staff; involvement of frontline health workers; a network of laboratories; and IT-enabled infrastructure for dissemination of disease surveillance data on a weekly basis.

Yet, every year, unnamed and unidentified diseases continue to kill or sicken hundreds of people across the country. Some of them remain a mystery despite resurfacing in a particular region almost as an annual phenomena.

One such is life-threatening *chamki fever* or encephalitis that grips Bihar's Muzzafarpur district every summer since 1995. The fever, which impairs functioning of the brain, primarily affects children and is the cause of hundreds of deaths in this impoverished district. Last year, the fever infected 653 children and caused 164 deaths. So familiar are people with its symptoms that at the first signs they rush their children to hospitals. The government sets up camps for treating and investigating the illness. Occasionally, the outbreak attracts the attention of researchers who visit the area because of personal interest. But all that are available so far are a plethora of hypotheses that implicate everything from pesticides, heat strokes, toxins in litchi fruit to undernourishment among children in the disease. This year the region has witnessed a mild impact of the disease—only 95 encephalitis cases and 12 deaths till June 30. Strangely, no one knows what has helped improve the situation.

A THIRD OF THE FEVER OUTBREAKS IN THE COUNTRY GO UNDETECTED BECAUSE OF LIMITED DIAGNOSTICS CENTRE AND POOR TESTING

An equally mysterious disease has been doing rounds in neighbouring Uttar Pradesh since 2005, when it resurfaced after going into hiding for 30 years. Initially, the authorities labelled it as Japanese Encephalitis (JE), a viral brain infection spread by mosquitoes, and focused on vector control and vaccination. But children continued to fall ill in Gorakhpur and neighbouring districts. In 2007, the National Institute of Virology (NIV), Pune, found enterovirus in the patients but could not link it to the disease. The symptoms of enterovirus infections and JE are similar. The only difference is that the fever caused by enterovirus stretches up to 15 days as against JE which lasts about a week. In 2017, scrub typhus, a mite-borne disease, was held responsible for the illness even though symptoms were atypical. Without any knowledge of the pathogen, the outbreaks rage uncontested.

WHO IS TO BE BLAMED?

IDSP has been designed for early detection of disease outbreaks and diagnosis of mysterious diseases through syndromic surveillance, which is essentially

PHOTO: REUTERS

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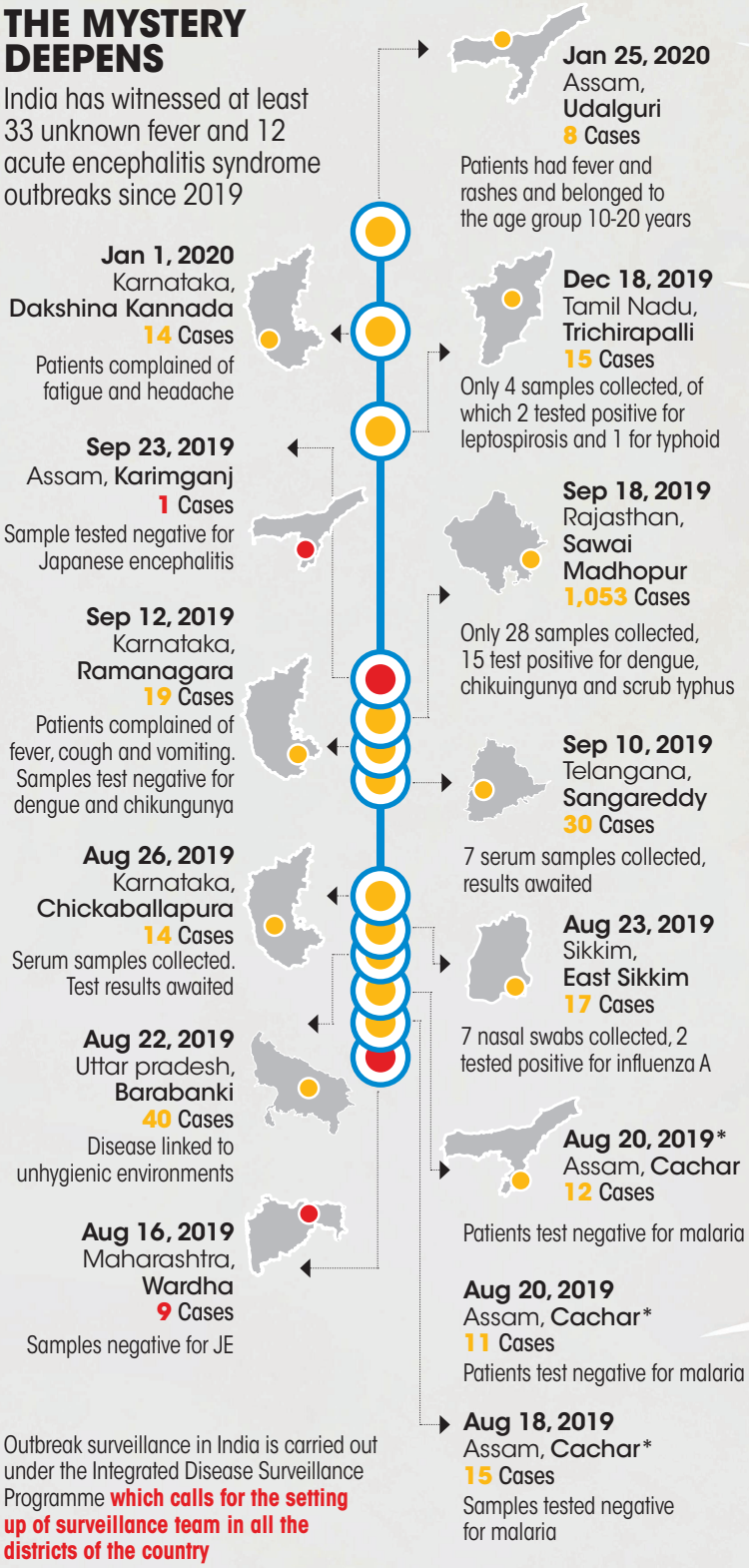
The Nipah virus disease outbreak in Kozhikode district of Kerala in May 2018 infected 200 people and claimed 17 lives

monitoring people's health on a real-time basis. The first round of surveillance activities are carried out by the frontline health workers, including accredited social health activists or ASHA, village volunteers and paramedical staff, who during their routine visits to households keep a lookout for those suffering from six symptoms: fever, cough for less than two weeks, acute flaccid paralysis in adults, diarrhoea and jaundice and unusual events causing death or hospitalisation. IDSP classifies these as indicators of 22 major diseases. They are then expected to fill up the suspected case or S-form for the patients, analyse the data to figure out if the numbers are higher than the previous records for the region and inform the district medical officer. The data is then sent to IDSP. The health workers also collect basic test samples and direct patients to doctors. At the district level,

THE MYSTERY DEEPENS

India has witnessed at least 33 unknown fever and 12 acute encephalitis syndrome outbreaks since 2019



Outbreak surveillance in India is carried out under the Integrated Disease Surveillance Programme **which calls for the setting up of surveillance team in all the districts of the country**

Fever Acute encephalitis syndrome

* Outbreaks in different villages in the same district
Source: Weekly outbreak update by Integrated Disease Surveillance Programme

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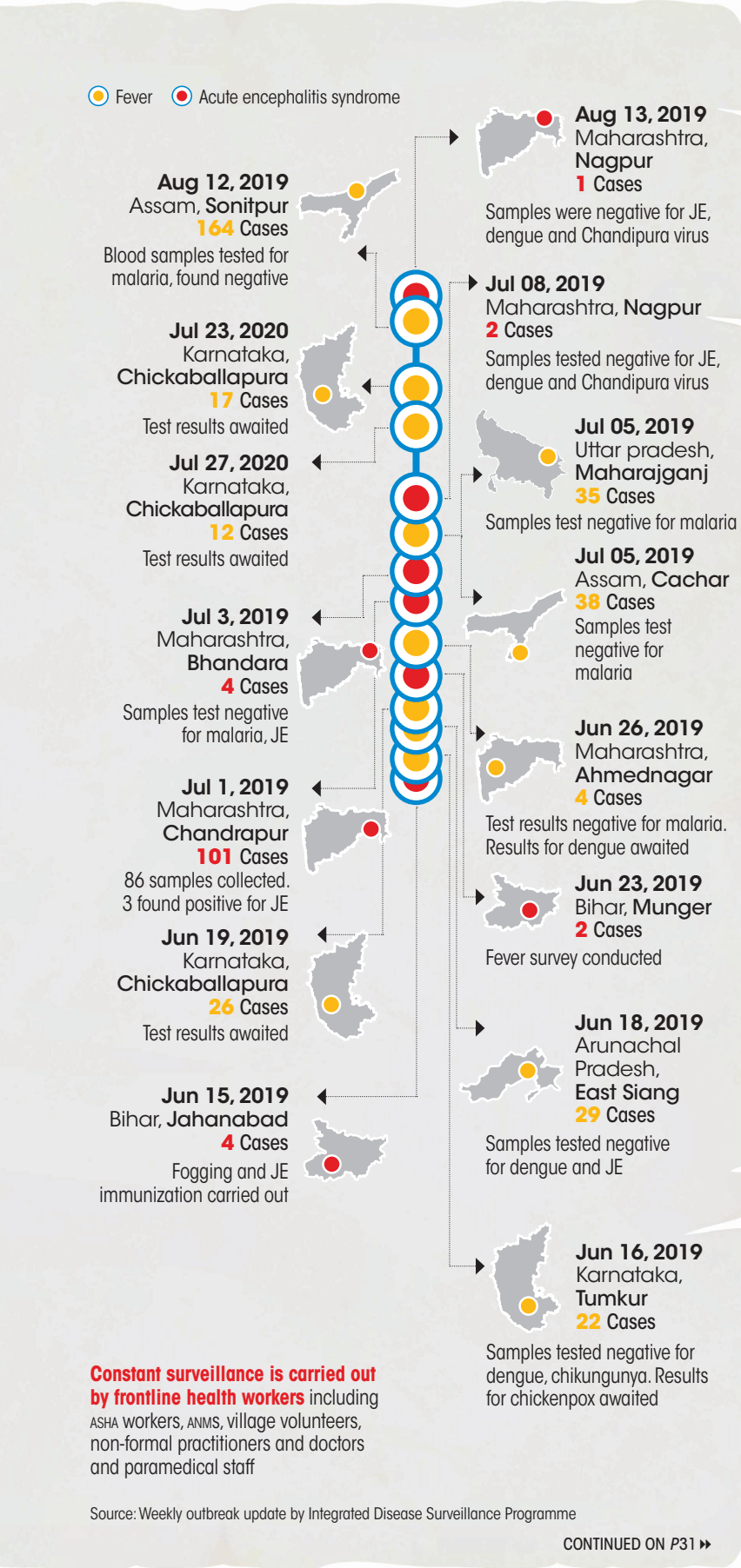
government and private hospitals along with medical colleges are expected to raise an alarm if there are "clustering of cases" from the same locality on a given day or on consecutive days. According to IDSP manual, doctors at the outpatient department (OPD) should refer such suspected cases of a disease outbreak to the laboratory. At the end of every week, the hospital superintendent is expected to fill up a presumptive or P-form based on the provisional diagnosis and upload it on the IDSP website. Labs across districts also need to fill up the laboratory confirmed or L-form based on their investigation. This too is uploaded on the IDSP site.

However IDSP no longer works the way it was conceptualised, says Rajan R Patil, epidemiologist and associate professor at the School of Public Health, SRM University, Tamil Nadu. He was involved in setting up IDSP as part of his UN assignment. "Currently, the surveillance work is being done in a mechanical manner. Instead of monitoring and providing data on a real-time basis, people are filling the data after weeks and even months, and the weekly bulletin is often given retrospectively," he says, adding that this defeats the very objective of early detection of outbreaks and averting large-scale sickness and deaths due to infectious diseases. His claims are not unfounded.

A DISTURBING PAUSE

As on July 21, IDSP on its portal provided weekly alerts till March 16-22, which had inputs from only 17 states and Union Territories. The next day, it released two more alerts for the weeks of March 23-29 and March 30-April 5. While the update for March 23-29 provided consolidated data related to only COVID-19 and redirected to the Union health ministry website for more details, the last alert provided data on two outbreaks.

Down To Earth (DTE) analysed the weekly reports of IDSP for 2019 and 2020 (till March 22) and found that it has recorded 33 outbreaks of fever and



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another 12 outbreaks of AES during the period (see 'The mystery deepens', *p*28). Fever outbreaks are reported from just 10 states—Karnataka, Assam, Tamil Nadu, Meghalaya, Arunachal Pradesh, Maharashtra, Uttar Pradesh, Sikkim, Telangana and Rajasthan. In most cases, the cause of fever remained unknown. DTE also found that IDSP does not follow all disease outbreaks. For instance, its weekly alerts do not include this year's mystery outbreak in Odisha's Malkangiri district. It also did not document the mysterious fever outbreak in Gujarat's Surat district in September 2019 that was widely covered by the media. In the absence of an investigation by IDSP, the government doctors in Surat maintain that the outbreak was caused by dengue even though more than 25 per cent of the patient's tested negative for the disease.

Another trend observed by DTE is that in 12 of the 52 weeks in 2019, the alerts did not mention how many states uploaded data. In other weeks, there was a discrepancy in the number of states and UTs mentioned in the total tally and in the description list of the outbreaks. For example, the alert for the first week of April 2019 says 35 states and UTs shared their records and 25 had outbreaks, but the description of outbreaks was available only for 15 states and UTs. This indicates a lackadaisical approach to data by an organisation that has been bringing out weekly alerts since 2007; data collection and dissemination is, in fact, one of its primary functions.

IDSP also seems to lose interest in the outbreaks after initial investigation. Most weekly reports mention that the disease is under surveillance but there is rarely any update on this later. In its monthly alerts, IDSP provides the details of investigation for just one disease. But the last monthly alert is for September 2019. While the outbreak could have been investigated further by the state governments, as health is a state subject, information on the outcomes are not

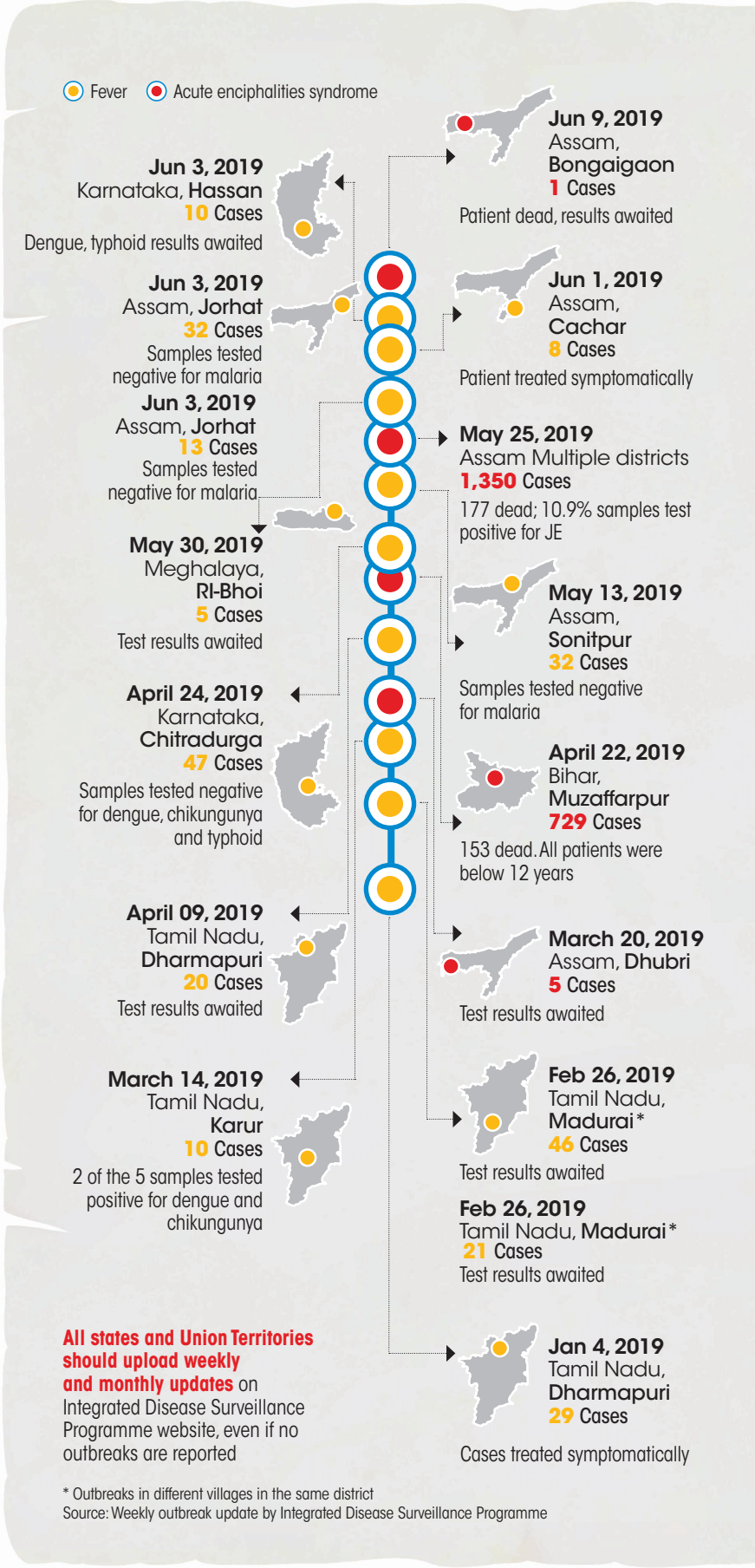
available in the public domain. DTE even tried to see if there are any published studies on disease investigations, a search in *PubMed*, an online database of biomedical and life sciences research literature for the term "integrated disease surveillance programme" threw up 16 results. None of them were on fever or AES outbreaks in 2019 and 2020.

DTE sent multiple emails to officials working under IDSP in states that regularly report mysterious fever to understand the final outcome of their investigation, but did not receive any response. Its request for an appointment with Sujeet Kumar Singh, director of IDSP and NCDC, was met with silence.

TAKE A CLOSER LOOK

The reason for IDSP's failure may not be as straightforward. Under the programme, all districts should have disease surveillance committees. However, the Parliament reply by Ashwini Kumar Choubey, Minister of State, Ministry of Health and Family Welfare, on July 9, 2019, shows only about half, or 380 of the 739, districts in the country have such committees in place to monitor disease trends and respond to outbreaks in early rising phase.

The elaborate arrangement also gets hindered by limited diagnostic facilities, faulty collection and testing of samples, suggests a 2019 study paper published by researchers and the directors of multiple government agencies, including NCDC, NIV and the Indian Council of Medical Research. The researchers had analysed outbreaks in 2017 and pointed out that even simple viral and bacterial infections such as dengue, JE and influenza go unidentified at times because of poor diagnostics. At least a third of outbreaks of fevers of unknown origin in the country go undiagnosed, they say in the paper, published in the *Indian Journal of Medical Research*. According to IDSP site, there are just 114 labs in the country. The lack of interest is also visible through the fact that budget allocated under the scheme is



49%
districts do not have the mandatory disease surveillance committees

29%
districts have vacancies for epidemiologists

382
posts lie vacant in Integrated Disease Surveillance Programme

23
of the 43 emerging and re-emerging viral diseases in India are zoonotic

seldom spent. In 11 of the 13 years between 2004-05 and 2016-17, expenditure was lower than the allocated budget. The last expenditure information is available on the IDSP portal till October 2017.

An April 2019 study published in the *Clinical Epidemiology and Global Health* highlights that researchers or institutes seldom adhere to NCDC's 10-step outbreak handling methodology. These are: determining the outbreak; confirming the diagnosis; defining it; searching for cases; generating a hypothesis using findings; testing the hypothesis with analytical study; drawing conclusions; comparing it with established facts; communicate the findings; and then executing preventive measures.

The report, which reviewed 136 articles on outbreak handling in India between 2008 and 2016, found that all the 10 steps were followed in only during 16 per cent of the outbreaks and in only 24 per cent of the cases proper analytical study was conducted (step 6). In 98 per cent of the outbreaks, researchers were more interested in arriving at the conclusion without following other steps.

LIMITED SCOPE

In 2015, a Joint Monitoring Mission set up by WHO and the Ministry of Health and Family Welfare, assessed IDSP and highlighted that it is limiting the scope of epidemiological studies of diseases by not collecting mortality data. The mission also raised concerns over the fact that IDSP looks at only 22 diseases, including malaria, dengue, chikungunya and AES that are already monitored by the National Vector Borne Disease Control Programme. They also pointed out that IDSP was not investigating zoonotic diseases despite the fact that it is just a matter of time that one of the emerging/re-emerging diseases become virulent and result in a major pandemic.

A THIRD OF THE FEVER OUTBREAKS IN THE COUNTRY GO UNDETECTED BECAUSE OF LIMITED DIAGNOSTICS CENTRE AND POOR TESTING

Even the 2019 paper identifies 43 emerging and re-emerging viral diseases that could affect India—23 of these are zoonotic in nature. One such is Chandipura virus that has emerged as a major encephalitic pathogen in India in recent years. The virus, spread by sandflies, has caused outbreaks in Andhra Pradesh (2004, 2005, 2007 and 2008), Gujarat (2005, 2009-12) and Vidarbha region of Maharashtra (2007, 2009-12), according to a study published in *The Open Virology Journal* in August 2018. Similarly, scrub typhus is being reported from newer geographies. The disease, earlier found in Himachal Pradesh, was implicated for the mysterious fevers in Uttar Pradesh's Gorakhpur district in 2018. Even the Nipah virus, first reported in Siliguri in 2001, had reached Kerala in 2018.

Cutaneous leishmaniasis, JE, scrub typhus and leptospirosis are spreading to a much wider area at an alarming rate in the past 68 years, write Ramesh C Dhiman of the National Institute of Malaria Research and Aakanksha Tiwari of Banaras Hindu University in a 2018 research paper. "Sudden outbreak of rare disease like Kyasanur Forest Disease can be fatal due to unavailability of strategies and policies to fight against them," they write in the paper published in the journal *Medical Reports and Case Studies*.

They advise that India should strengthen the public health surveillance systems and provide quick medical support to control the damage caused by outbreaks. The question remains how?

THE OTHER SCARE

India needs to revisit public health system to fight the rising threat from disease outbreaks

THE FAILURE of the government machinery to identify the disease has meant that individual researchers and doctors often try to unravel mystery outbreaks. "But in the absence of support from the government, a consensus on the cause is rarely reached," says Vipin M Vashishtha, consultant paediatrician in Bijnor, Uttar Pradesh, who was part of the team that unraveled the mystery fever in Saharanpur district.

Between the 1980s and 2000s, there were reports of an average of 400 children dying each year in Saharanpur. In 2002, after 100 children died in two weeks in September, the Industrial Toxicology Research Centre, now renamed Indian Institute of Toxicological Research, visited the area and blamed it on a pesticide. Soon, the National Institute of Communicable Diseases (now NCDC) stepped in and said Japanese encephalitis virus is killing the children. As the deaths continued, Vashishtha and a group of independent doctors studied the patients in 2007 and found that the toxic pods of a weed, *Cassia occidentalis* (locally called *kasondi* or *pamaad*), is the cause of the illness. Children, especially from poor families, ingested the pods which then affected their liver, brain and muscles. They termed the illness hepatomyoencephalopathy. However, cases continued to be reported. In 2009, when 25 children died because of the illness, Vasistha claimed it was because the local authorities did not spread awareness about the toxic pod.

In most outbreaks where the disease remains unidentified, doctors simply treat patients for the symptoms and the local administration follows it up with sanitation and sensitisation drives.

Milind M Gore, who set up National Institute of Virology (NIV)'s lab unit in Gorakhpur in 2008, says, "We would be able to solve the problem of infectious diseases in the country if we can solve the Gorakhpur puzzle." But identifying the aetiology of a disease is not easy. "The search often leads to wild goose chases and you need patience," says Lalit Kant, former head of epidemiology and communicable diseases division at the Indian Council of Medical Research.

It also requires an experienced eye, explains Prabir Chatterjee, epidemiologist formerly with the State Health Resource Centre, Chhattisgarh. It is difficult to identify even a well-known disease if it is new to an area. If a patient from Gujarat with symptoms of Kala Azar visits the Christian Medical College (CMC), Vellore, in Tamil Nadu, doctors there are less likely to have encountered the disease and might classify it as a mysterious disease, Chatterjee explains. A well-read doctor would be able to guess it but he or she would still need help in disease confirmation and treatment.

So the way to identify a mysterious disease involves a thorough clinical, biochemical, histopathological and microbiological investigations. In case, the disease has caused deaths, autopsies must be performed to reach at conclusions. The second stage of identification should consist of epidemiological investigations

PHOTO: ADITHYAN P C / CSE

The mysterious fever in Saharanpur district of Uttar Pradesh has on an average killed 400 children a year since the 1980s

"IDSP is not what we need"

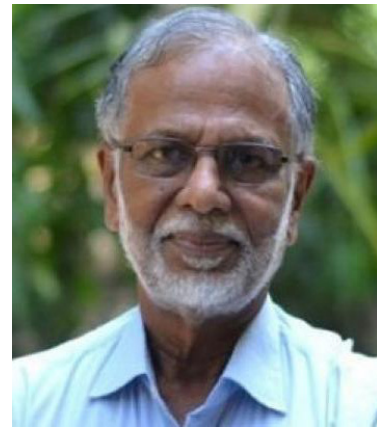
T JACOB JOHN, virologist and former professor at the Christian Medical College, Vellore, has closely monitored mysterious outbreaks over the decades. He says no agency in the country is equipped to investigate outbreaks

India has seen several outbreaks of unknown aetiology. Can we hold the Integrated Disease Surveillance Programme (IDSP) responsible for not identifying them?

No. They are like the post office. You cannot hold them responsible for a bad message. IDSP receives messages and forwards them to the correct authority —National Centre for Disease Control (NCDC), under the Directorate General of Health Services (DGHS) which is designed to provide services and not investigate outbreaks. DGHS and NCDC have a small set up that is unfit for a country with 1.38 billion people. IDSP is doing its job, though with extensive delays, but they are not what we need for investigating outbreaks.

Then what do we need?

We need a public health system. Disease surveillance is a tool to notify diseases to public health experts. If there is no public health system, disease surveillance becomes an exercise for collecting data for updating knowledge. True surveillance is information for action, then and there—not delayed. IDSP cannot do this as the design of the health management system in India is deeply flawed. The human health management, which is both prevention and treatment of diseases, is of dismally low standard in the country. The outbreaks in Saharanpur and Muzzafarpur have been going on for decades, but health management system did not take them seriously. The



truth is that they did not know how to handle the outbreaks. They were not serious about the identification of the disease and its causation. NCDC is not competent enough to solve the problem.

Who is responsible for investigating outbreaks then?

In countries with good health management system, the public health system is responsible for investigating outbreaks. In the absence of public health, agencies like NCDC try to investigate. They take the "responsibility" to do their best, but they are without "accountability". So, if they fail, they fail. If they would have been accountable, then when they failed, they would have brought in the best experts from the country.

Outbreaks can be of diseases with known or unknown causes. Investigation of the former is easy. The faculty of the local medical college can double up and investigate them. The objective is to detect the risk-factors and take immediate remedial measures. Investigation of the latter involves first discovering the cause and then determining the risk factors and finally stopping the outbreak. If the cause can be easily detected, as is in most instances, they need to be handled like an outbreak of known cause. Here is the tricky problem: all outbreaks need not be due to infectious disease. Inexperienced and untrained investigators tend to assume that an outbreak has to be due to a transmitted agent, hence infectious.

Can we improve the situation?

In India, I don't see any honest desire to improve the situation. We—the Union health ministry, healthcare experts in government and private sectors—are arrogant enough to assume every disease can be treated and there is no need to "waste money" on prevention. If India wanted to prevent diseases, it would have improved the situation decades ago. But that would involve some expenditure. If that is considered as waste, then we will not improve. If we spend that 2-3 per cent GDP on public health, it will push the GDP higher. India cannot become a 5-trillion dollar economy without establishing a public health system in the country. It is a well-kept secret in the profession that doctors (healthcare experts) are the worst enemy of public health as there is huge profit in disease-care industry. So I ask: Do we really want to improve?

to identify risk factors, says Vashishtha. This requires the deployment of a team that includes epidemiologists, pathologists, neurologists, toxicology and public health experts, and paediatricians.

"Skilled and experienced people are especially important in recognising a zoonotic disease," says Kant. The problem is more with new and emerging diseases as there are no diagnostic tests and the doctors have to diagnose on the basis of symptoms. So, for a new disease of suspected zoonotic origin working in collaboration with a veterinarian would be ideal. "This synergy between agriculture experts and doctors helped India contain the bird flu outbreak," he says.

Synergy was also at play during the Nipah outbreak in Kerala in 2018. "We have excellent examples of promptly recognising a serious outbreak and quickly getting the act together to control an epidemic which could have been disastrous," says George M Varghese, professor at the Department of Infectious Diseases, CMC, Vellore. An unusual infectious disease was noted by an astute clinician, the sample was sent to a reference laboratory which then quickly identified it as Nipah virus in 2018. "In all my years of work, I have not seen an outbreak handled as well in India as that of Nipah in Kerala. Education has paid dividends and people are aware," he said. Public health infrastructure too is much better in the state. The lesson from this success is that we need to work on public health infrastructure, he says.

Unfortunately, there is a shortage of such health infrastructure as well as skilled and experienced persons in the country. Capacity building was thus one of the major recommendations made by the Joint Monitoring Mission set up by the World Health Organization (WHO) and the Union Ministry of Health and Family Welfare (MOHFW) in 2015. It had found that the government had only 407 epidemiologists as against the sanctioned posts of 703. There was a 33 per cent shortage of microbiologists and 80 per cent shortfall in veterinary doctors. The situation is equally dismal now. To handle the COVID-19 pandemic, states are scrambling to hire 227 epidemiologists, as per the media reports. The desperation started when Preeti Sudan, secretary, MOHFW, wrote a letter to all state governments, on April 7, to immediately fill up vacancies for epidemiologists in 216 districts. The letter indicated that IDSP has 382 vacancies at present.

IN MOST OUTBREAKS WITH INCONCLUSIVE INVESTIGATIONS, DOCTORS TREAT PATIENTS ON THE BASIS OF SYMPTOMS AND LOCAL ADMINISTRATION USUALLY FOLLOW IT UP WITH SANITATION AND SENSITISATION DRIVES

If the situation does not improve, experts warn that the biggest challenge in the future will be the country's inability to handle zoonotic diseases, which are usually behind most mysterious diseases and are showing regular resurgence. Globally over half of the 1,407 human pathogens are zoonotic and in many cases can cause fevers of unknown origin, warns a 2007 analysis published in the *Infectious Disease Clinics of North America*. Developing countries like India are at a higher risk of fevers of unknown origin than developed countries, it says, and for a reason. The country's public health infrastructure is so weak that many times even common diseases do not get identified in time.

One of the fundamental reasons for this is that doctors in the country are not trained to carry out basic research and they lack curiosity, says T Jacob John (see 'IDSP is not what we need', *p*36). He says if a person with fever symptoms comes for treatment, most doctors think only of malaria, dengue or typhoid. Similarly, if a child with seizure comes to the doctor, it is identified as encephalitis in most cases. Rajib Dasgupta, professor at the Centre of Social Medicine and Community Health at the Jawaharlal Nehru University, Delhi, is optimistic. He says, "Public health systems are built brick by brick, the experience of COVID-19 shall also contribute to the strengthening of the surveillance system." DTE

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