The mystery behind mysterious diseases

A *Down To Earth* investigation

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Mysterious diseases

• February 2020: 15 deaths in just one village, Kenduguda, Malkangiri district, Odisha. Population of the village is just 400. The patients complained of swelling in legs and stomach, and acute respiratory problems. Medical team from Malkangiri suspected that the deceased could be suffering from kidney or heart ailments or anaemia or tuberculosis.

• September 2019: 1053 cases of fever in Village Chaan in Sawai Madhopur. Just 28 blood samples collected. 15 found positive for Dengue, Chikuiningunya and Scrub Typhus. Just 15 throat swab samples collected and 3 were positive for diphtheria pathogen. 570 blood slides prepared, 2 were positive for malaria. Still left many cases undiagnosed.

• August 2018: fever deaths in six districts of Uttar Pradesh. In Bareilly, 202 deaths reported. Death audit was carried out in 24 cases and out of these, 2 were found to be due to malaria while others were attributed to chronic diseases (TB, kidney failure, heart failure, asthma). Reason for 178 deaths is not known.
Mysterious diseases

• We have many examples of long standing mystery diseases

• Since 2005, encephalitis cases reported from Gorakhpur and surrounding districts: The disease re-emerged after 30 years. JE? Enterovirus? Scrub typhus?

• Since 1995, cases of encephalitis reported from Muzzafarpur and surrounding districts: pesticides? Heat stroke? Litchi toxin? This year, just 12 deaths in Muzzafarpur till June end, reason for decrease unknown

• Since 1980’s, cases of encephalitis reported from Saharanpur and surrounding districts: JE? Pesticides? Cassia seed toxins?
Surveillance in India

- Disease outbreaks are monitored by the National Centre for Disease Control. It runs a special programme—Integrated Disease Surveillance Programme—to do this.

- IDSPs mission: strengthen disease surveillance in the country for epidemic prone diseases and provide early warning so that timely public health actions can be taken.

- They have presence in each district. Data is collected from each village. Village health workers, ANMs, ASHAs, doctors and lab technicians are all involved in the process.

- Village health workers carry out syndromic surveillance. They look for 6 symptoms that cover a total of 22 diseases. These symptoms include fever, having cough more than three weeks duration, acute flaccid paralysis, diarrhoea, jaundice and unusual events causing death or hospitalization.

- District disease surveillance team collects all data: Suspected, probable and laboratory confirmed.
Since 2007, IDSP has been publishing a weekly outbreak alert. Data is available online since 2009. As many as 30-40 outbreaks reported per week, IDSP says.
What did DTE find?

• Down To Earth analysed weekly outbreak reports available on IDSP for the year 2019 and 2020 (alerts till March included)

• We found reports of 33 outbreaks of fever and 12 of AES

• During investigations, samples were collected and tested for malaria, dengue, chikungunya and scrub typhus. Tested negative for these pathogens in most samples. Results of additional tests and additional surveillance not available in public domain

• Fever outbreaks are reported from just 10 states in the country: Karnataka, Assam, Tamil Nadu, Meghalaya, Arunachal Pradesh, Maharashtra, Uttar Pradesh, Sikkim, Telangana and Rajasthan

• Searched PubMed for the term "integrated disease surveillance programme" threw up 16 results. None of them were on fever or AES outbreaks in years 2019 and 2020. There was one study analysing data from 2017
**The Mystery Deepens**

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

- **Jan 1, 2020**
  - Karnataka, Dakshina Kannada: 14 Cases
  - Patients complained of fatigue and headache

- **Sep 23, 2019**
  - Assam, Karimganj: 1 Case
  - Sample tested negative for Japanese encephalitis

- **Sep 12, 2019**
  - Karnataka, Ramanagara: 3 Cases
  - Patients complained of fever, cough, and vomiting

- **Aug 26, 2019**
  - Karnataka, Chickballapur: 16 Cases
  - Serum samples collected, test results awaited

- **Aug 22, 2019**
  - Uttar Pradesh, Varanasi: 40 Cases
  - Disease linked to unhygienic environment

- **Aug 16, 2019**
  - Maharashtra, Wardha: 9 Cases
  - Samples negative for JE

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

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**Constant Surveillance is carried out by frontline health workers including raw workers, village volunteers, non-formal practitioners and doctors and paramedical staff.**

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**Cases treated symptomatically**

Source: Weekly outbreak update by Integrated Disease Surveillance Programme

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**All states and Union Territories should upload weekly and monthly updates on Integrated Disease Surveillance Programme website, even if no outbreaks are reported.**

* Outbreaks in different villages in the same district

Source: Weekly outbreak update by Integrated Disease Surveillance Programme
The curse of emerging and re-emerging diseases

• Analysis of data for year 2017 by researchers from NCDC and ICMR shows that aetiological agent could not be identified in 1/3 to 1/4 of the fever outbreaks. The researchers identified 43 emerging and re-emerging viral diseases that threaten India. 23 of these are of zoonotic origin

• Zoonotic diseases are spreading across the country - Nipah was reported from Siliguri in 2001 but led to outbreak in Kerala in 2018. Scrub typhus traditionally reported from Himachal Pradesh but now affecting children in Gorakhpur. Other diseases that are spreading at an alarming rate are JE, leptospirosis, cutaneous leishmaniasis and Kyasanur forest disease

• These can be fatal in absence of strategies and policies to fight them. In 2015, a Joint Monitoring Mission advised IDSP to look at zoonotic, emerging and re-emerging disease

• The National Health Policy 2017 advocates the need for districts to respond to the communicable disease in the locality. Zoonotic diseases are mentioned but only in reference of known ones like rabies
The curse of emerging and re-emerging diseases

- As environment degrades and contact between natural hosts of these pathogens and humans increase, we can expect many more new diseases.

- These diseases can derail life and economy. COVID-19 is a good example. Outbreaks of swine flu, Zika virus disease, dengue, chikungunya, JE, Kyasanur forest disease, Chandipura virus, Crimean-Congo haemorrhagic fever are common.

- In absence of effective surveillance, they can easily reach pandemic proportions.
How to solve the mystery?

- ISDP reports are uploaded retrospectively. The last weekly alert is from March/April.

- All states and Uts do not report. The weekly update for March 16-22 is based on information received from just 17 states and UTs.

- There is a discrepancies in the number of states and UTs mentioned in the total tally and in the description list of the outbreaks. Lack of respect for data.

- Last monthly alert on the IDSP site is for September 2019. The monthly reports provides details of just 1 outbreak. Fever outbreaks not detailed in any alert in 2019.

- Allocated budget is not used to improve. In 11 of the 13 years between 2004-05 and 2016-17, expenditure was lower than the allocated budget. The last expenditure information on IDSP site is for 2017-2018 (till October 2017).
How to solve the mystery?

• Real time monitoring of disease outbreaks needed. Findings should be available in a transparent manner

• Investigating teams should include epidemiologists, pathologists, neurologists, toxicologists, public health experts and paediatricians. NCDC should confirm findings and inform people

• Human resource capacity is important. There is a shortage of epidemiologists, microbiologists and veterinarians. Even medical doctors need to be taught the basics in outbreak investigations

• Authorities should be held accountable for the morbidity and mortality

• Public health systems needs to be improved. More Investment needed
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