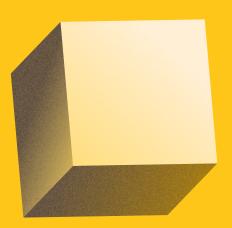
THE HINDU ANALYSIS

27th March 2024 by saurabh pandey







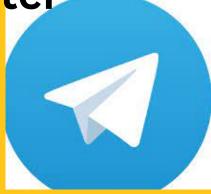
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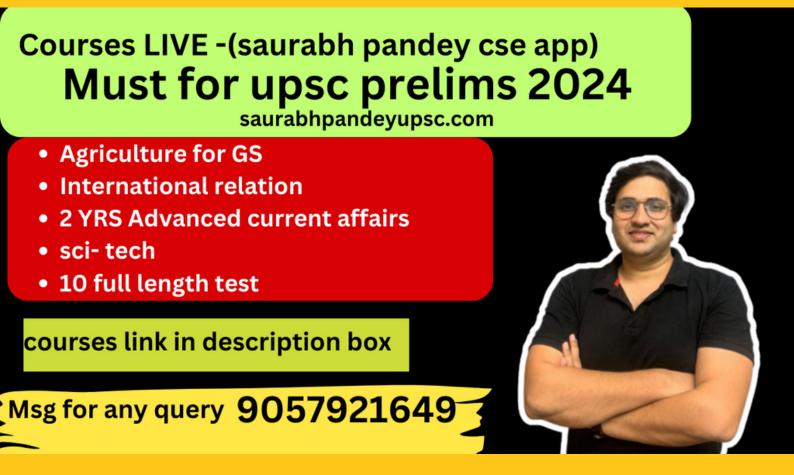
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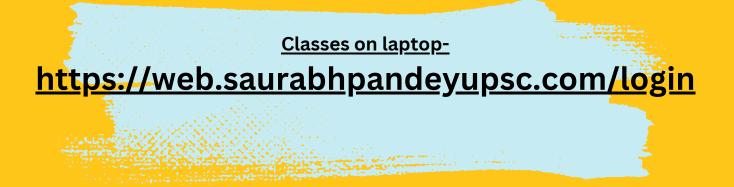
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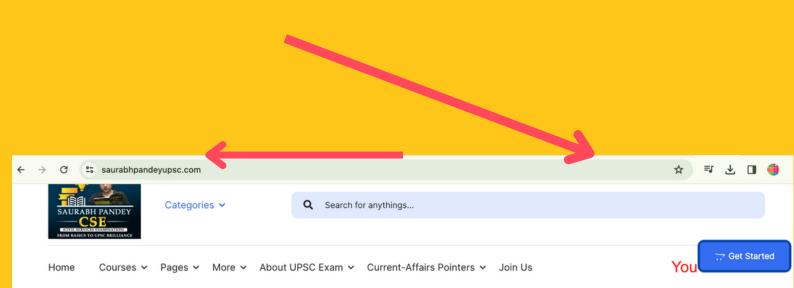


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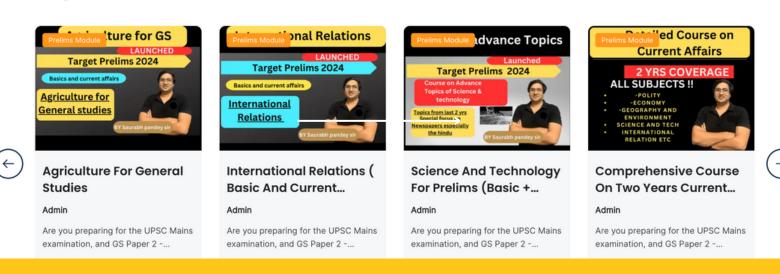
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Inaccessibility and cost cripple efforts to treat sickle cell disease

People from marginalised tribal communities, face a battle even to access basic healthcare and diagnostics. They also face an under-resourced health system, inadequate information, and high expenditure. Treatments like CRISP cost \$2:3 million and bone marrow donors are difficult to find

Sarojini Nadimpally Gargi Mishra Keertana K. Tella

hen five year-old Suraj was debilitated with a persistent fever, his family took him to the district hospital in Napada in western Odisha. The hospital directed them to the Veer Surendra Sul Institute of Medical Sciences around 250km from their village. At the institute, Suraj underwent a diagnostic test called haemoglobin electrophoresis ot detect whether he had skile coll disease (SCD). When the tests confirmed disease (SCD), when the tests confirmed disease (SCD), when the tests confirmed stirt in by a stirt for blood transitisons. Surdis story came up during our work of the National Human Right Commission in 2019. It provides a sumptee form marginal Human Right Commission in 2019. It provides a sumptee form marginal the theol character and signostis. Margin with the Walkow with the balkow and the share face even to access basic healthcare and signostis.

diagnostics. It is, however, the beginning of an arduous battle with an under resourced health system, inadequate information, and high expenditure. In light of these realities, and the global discussion on advances in human genome editing, the question that becomes especially pertinent is whether these especially pertinent is whether these of such experiences.

conversations allow for and are cognisant of such experiences. SCD is an inherited haemoglobin disorder in which red blood cells (RBCs) become crescent or sickle-shaped due to a genetic mutation. These RBCs are rigid and impair circulation, often leading to many disorder and the set of the set of the set of the many disorder and the set of the set of

a genetic mutaton. These RBCs are rigid and impair circulation, often leading to anaemia, organ damage, severe and episodic pain, and permature death. India has the third highest number of SCD births, after Rbgeria and the Democratic Republic of the Congo. Regional studies auggest approximately 15,000-05,600 babies with SCD are born in India every year, mostly in tribal commanifies. According to the 2023 Guidelines for National Programme for Prevention and Management of Sickle Cell Disease', of the L3C crope persons screened in different states, about 8.75% (9.96 lakh) tested positive. It is also one of the 27 specified" disabilities listed in the Schedule of the Rights of Persons with Disabilities Act 2016.

2016. Access to treatment a major issue in 2022, the Government of India launched the National Sickle Cell Anaemia Elimination Mission, to eliminate SCD by 2047. At present, however, treatment and care for SCD remains grossly inadequate and inaccessible. States with a high prevalence of SCD particularly among their most marginalised populations, are discussed and the state of the state of the main travial basic care to those affected. An apposite example is the umavailability of the drug hydroxyurea. It lessens the severity of pain, reduces hospitalisations, and improves survival rates by increasing the size and flexibility of RBCs and lowering their likelihood of becoming sickle-shaped. Vet States are Largely unable to provide hydroxyurea for SCD patients, pointing to their inability to purchase, stock, and distribute the drug Even though the National Health Mission?

purchase, stock, and distribute this drug; byen though the Sational Health Mission's Essential Medicines List requires the drug level, hydroxytrea is currently only available in certain terturay-level facilities, such as medical colleges. Blood transfitsion is another important therapy for SCD, but is availability is imited to district level facilities. Most block-level commanity health centres don't offer them. Even during an emergency, families of SCD patients have or arrange for thood replacement units and pay for expensive private transport. Pain medications, from painillers to non-steroidal anti-inflammatories and opiolois, are also scarce. Borne marrow transplant for GDD, is the difficulty in finding matched donors, tent of reach for most SCD patients have be heigh cost of the treatment at private facilities, and long waiting times in public the time are at making care universally available.

Access to and equity of CRISPR In light of this, the application of the gene-editing technology called (SMSPR (short for 'Clustered Regularly Interspaced Short Palindromic Repeats') to treat SCD is important – for its novely and promise but also for the health



A colorised microscope image made availabl cell, left, and normal red blood cells of a pati

99

cetl, left, and normal red blood cetls of a patient with disparities it makes apparent. The US. Food and Drug Administration recently approved two gene therapies, Cagery and Lyfgmil, to treat SCD in popel agits and the treat schematic schematic cetters and the schematic schematic schematic patient schematic schematic schematic schematic cetters and schematic schematic schematic patient schematic schemat

use of gene therapies. CRLSPR in India Applications also pose ethical and legal applications also pose ethical and legal quandaries. The Kaitonal Guidelines for Stem Cell Research 2017 prohibit the commercialisation of stem cell therapies ethical trails, except for BMT for SCD Gene-editing stem cells is allowed only for invitro studies. The Guidelines also encourage the don't mandate the sharing of financial benefits resulting from the commercialisation of stem cell products with the donor or community. Further, the National Guidelines for Gene Therapy Product Development and

Sickle cell disease is an inherited haemoglobin disorder in which red blood cells become crescent or sickle-shaped. These RB/S are rigid and impair circulation, often leading to anaentia, organ damage, severe and episodic pain, and premature death

Clinical Trials 2019 provide guidelines for the development and clinical trials of gene therapies for inherited genetic disorders. India has approved a five-year project to develop CRISPK for skick cell anaemia. Under its Skick cell Anaemia Mission, the Council of Scientific and Industrial Research is developing gene-editing therapies for SCD. Around mission over 2020-2023. It is reportedly in the pre-clinical stage, with clinical trials awaited. However, the Guidelines need a

the pre-clinical stage, with cinneat trans awaited. However, the Guidelines need a stronger health inequity and discrimination perspective, addressing issues such as equitable opportunities for participate in clinical trials, and whether and how this therapy will be made available to those populations in future. Adopting and promoting advanced therapies like CRISPR in India require a comprehensive approach that accounts for inequities and disparities in the

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The Sickle Cell Team from JSS College in M ming a skit on sickle cell awareness at

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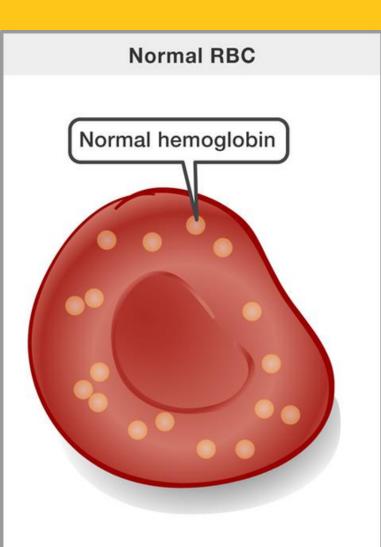


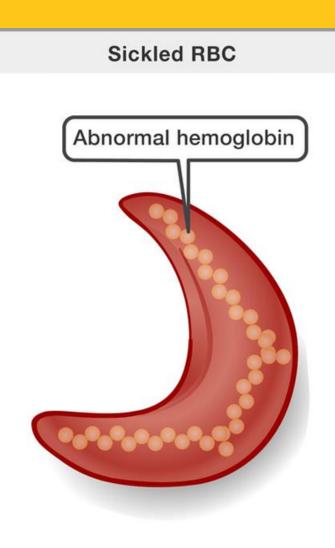


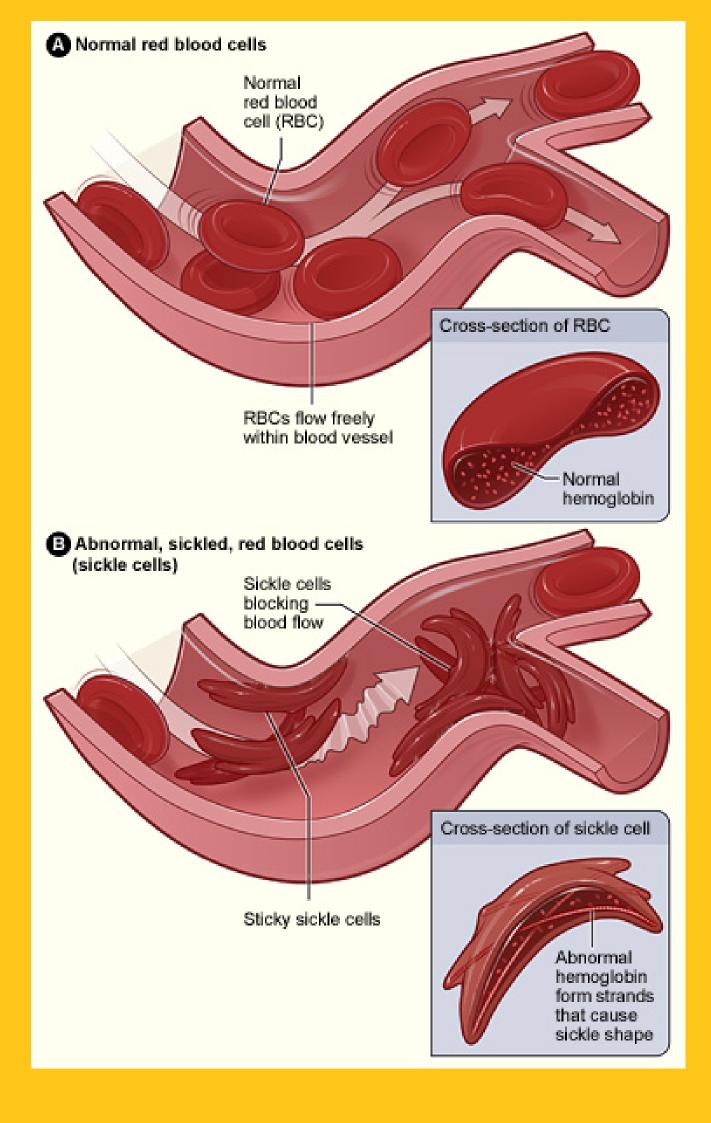
Sickle cell Anaemia

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- These RBCs are rigid and impair circulation, often leading to anaemia, organ damage, severe and episodic pain, and premature death.
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- In 2023, the Government of India launched the National Sickle Cell Anaemia Elimination Mission, to eliminate SCD by 2047. At present, however, treatment and care for SCD remains grossly inadequate and inaccessible.
- States with a high prevalence of SCD, particularly among their most marginalised populations, are falling behind in their efforts to reach out and provide basic care to those affected.
- Blood transfusion is another important therapy for SCD, but its availability is limited to district-level facilities.





 Bone marrow transplantation (BMT), until recently the other cure for SCD, is out of reach for most SCD patients due to the difficulty in finding matched donors, the high cost of the treatment at private facilities, and long waiting times in public hospitals.

Access to and equity of CRISPR

 In light of this, the application of the gene-editing technology called CRISPR (short for 'Clustered Regularly Interspaced Short Palindromic Repeats') to treat SCD is important — for its novelty and promise but also for the health disparities it makes apparent.



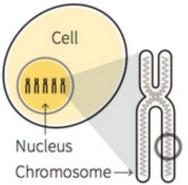
DNA editing

A DNA editing technique, called CRISPR/Cas9, works like a biological version of a word-processing programme's "find and replace" function.

Guide

molecule

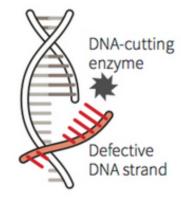
HOW THE TECHNIQUE WORKS



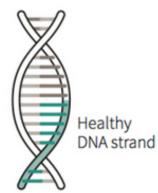


A cell is transfected with an enzyme complex containing: Guide molecule Healthy DNA copy DNA-cutting enzyme

A specially designed synthetic guide molecule finds the target DNA strand.

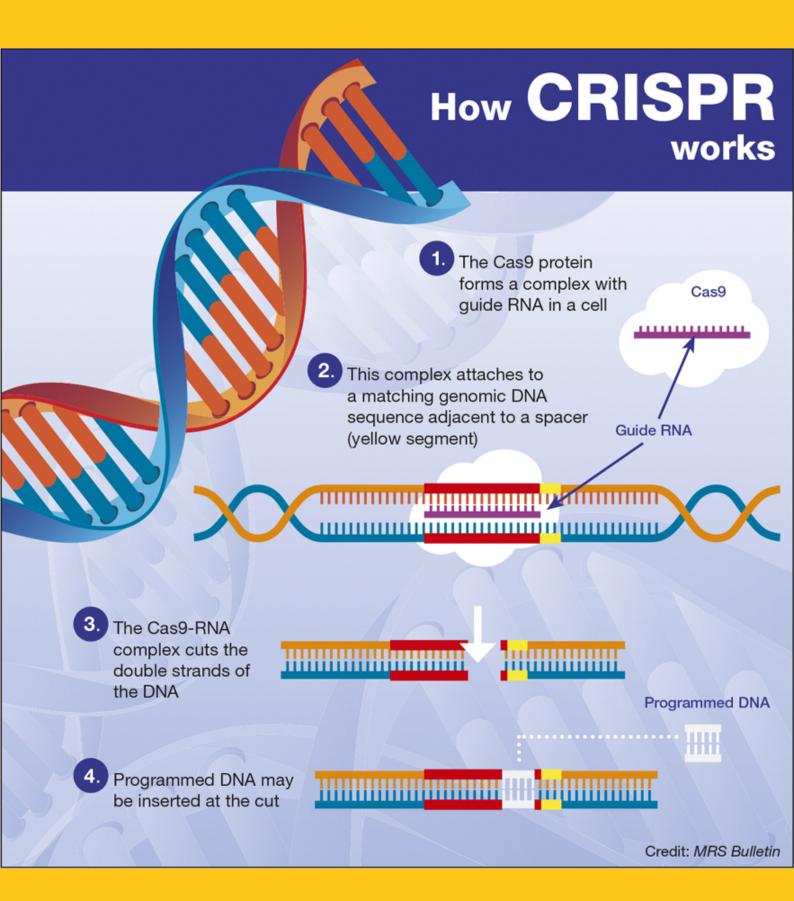


An enzyme cuts off the target DNA strand.



The defective DNA strand is replaced with a healthy copy.

Sources: Reuters; Nature; Massachusetts Institute of Technology





- The U.S. Food and Drug Administration recently approved two gene therapies, Casgevy and Lyfgenia, to treat SCD in people ages 12 and older.
- Casgevy, developed by Vertex Pharmaceuticals and CRISPR Therapeutics and also approved in the U.K., is the Dfirst CRISPR-based therapy to have received regulatory approval in the U.S. Lyfgenia, manufactured by Bluebird Bio, doesn't use CRISPR but depends on a viral vector to change blood stem-cells.





- Both treatments entail collecting a patient's blood stem-cells, modifying them, and administering high-dose chemotherapy to destroy the damaged cells in the bone marrow.
- The modified cells are then infused into the patient through a hematopoietic stem cell transplant.
- The treatments are expected to take up to a year and require several hospital visits





Crispr and SCA in india

- In India, CRISPR's possible medical applications also pose ethical and legal quandaries.
- The National Guidelines for Stem Cell Research 2017 prohibit the commercialisation of stem cell therapies and allow the use of stem cells only for clinical trials, except for BMT for SCD. Geneediting stem cells is allowed only for in-vitro studies.
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 Ifive-year project to develop CRISPR for sickle cell anaemia.

 Under its Sickle Cell Anaemia Mission, the Council of Scientific and Industrial Research is developing gene-editing therapies for SCD.





The need to curb black carbon emissions

What is black carbon and why is it harmful for the environment? Which sector in India is the biggest contributor of black carbon? How has the Pradhan Mantri Ujjwala Yojana helped in reducing the use of traditional cooking fuels?

EXPLAINER

<u>Chandrakiran Lakshmisha</u> <u>Kaushik Reddy</u>

The story so far: t the COP26 climate talks in Glasgow in November 2021, India pledged to achieve India piedged to achieve net-zero emissions by 2070, positioning itself as a frontrunner in the race to carbon neutrality. According to the Ministry of New and Renewable Energy, India had installed a renewable energy capacity of over 180 GW by 2023 and is expected to meet its target of 500 GW by 2030. While carbon dioxide mitigation strategies will yield benefits in the long term, they need to go hand-in-hand with efforts that provide short-term relief.

short-term relief. Why is black carbon relevant? Black carbon is the dark, sooty material emitted alongside other pollutants when biomass and fossif fuels are not fully combusted. It contributes to global warming and poses severe risks. Studies have found a direct link between exposure to black carbon and a higher risk of heart disease, birth complications, and premature death. Most black carbon emissions in India arise from burning biomass, such as cow dung or straw, in traditional cookstoves. According to a 2016 study, the residential sector contributes 47% of Industrise contribute a further 22%, diesel vehicles 17%, open burning 12%, and other sources 2%. Decarbonisation efforts in the industry and transport sectors in the past decade have yielded reductions in black carbon emissions, but the residential sector remains a challenge. Has PMUY helned?

Has PMUY helped? In May 2016, the Government of India said the Pradhan Mantri Ujiwala Vojana (PMUY) would provide free liquefied (PMUY) would provide free liquefied petroleum gas (LPG) connections to households below the poverty line. The



Clean cooking: Women make tea on an earther st primary objective was to make clean cooking fuel available to rural and poor households and reduce their dependence on traditional cooking fuels. The PMUY has established infrastructure to go with LPG connections, including free gas stores, depositis for LPG cylinders, and a distribution network. The programme has thus, been able to play a vital role in reducing black carbon emissions, as it offers a cleaner alternative to traditional fuel consumption. The programme has provided consections to over 10 crore households as of January 2024. However, in 2022-2022, 25% of all PMUY beneficiaries – 2.69 crore people – availed either zero LDG refil or only one LPG refil, according to RTI data, meaning they still relied entirely on traditional biomass for cooking. *The Hindu* fund in August 2023 that the average PMUY beneficiary household consumes only 3.5-4 LPG cylinders per year instead of

the six or seven a regular non-PMUY household uses. This means up to half of all the energy needs of a PMUY beneficiary household are still met by traditional fuels, which have high black carbon emissions. A shortage of LPG and higher usage of traditional fuels also affect women and children disproportionately. They are more prone to higher levels of indoor air pollution, causing many health issues and leading to premature deaths.

Susses and reading to premature deaths.
What is the government's role?
The key to enhancing the quality of life in these areas lies primarily in securing access to clean cooking fuels. While the future holds the promise of meeting energy needs in rural areas through renewable sources, the immediate benefits for rural communities are poised to come from using LPG.
In October 2023, the government increased the LPG subsidy to 5300 from

2200. But with rapid increase in LPG prices over the last five years, the cost of a H_2 -kg LPG cylinder, even with an additional subsidy, is still about 7600 per cylinder. Most PMUY beneficiaries find dung, firewood, etc. are 'free' alternatives. Prime Minister Narendra Modi announced a further price reduction of 7100 in March 2024, but this subsidy is everyted to be temporary. The

reduction of 7100 in March 2024, but this subsidy is expected to be temporary. The government has estimated that about \$20,000 crore will be spent on PMUY subsidies in 2024-2025, a figure that has continuously increased each year since the scheme's inception. While it is the rightful duty of the government to make clean fuel affordable through subsidies, the problem of low refill rates will persist if availability issues are not addressed. Another big hurdle to the PMUY's success is the lack of last-mile connectivity in the LPG distribution

success is the lack of last-mile connectivity in the LPG distribution network, resulting in remote rural areas depending mostly on biomass. One potential solution to this issue is the local production of coal-bed methane (CBM) gas by compositing biomass. CBM is a much cleaner fuel with lower black carbon emissions and investment. Panchayats can take the initiative to produce CBM gas locally at the village level, ensuring every rural household can access clean cooking fuel.

What about the global stage? As India navigates its responsibilities on the global stage towards long term decarbonisation, there is an urgent need to act. Prioritising black carbon reduction through initiatives such as the PMUY scheme can help india become a global leader in addressing regional health concerns and help meet its Sustainability Development Goal of providing alfordable clean energy to everyone an initigation. Recent estimates have indicated that mitigating residentiate emissions will avoid more than 6.1 lakid leaths per year from indoor exposure to air pollution. The authors work at the Center for Study of Science, Technology and Policy (CSTEP). What about the global stage?

THE GIST

Black carbon is the dark, sooty material emitted alongside other pollutants when biomass and fossil fuels are not fully combusted. It contributes to global warming and poses severe risks.

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Curb black carbon emissions

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The hindu analysis by saurabh pandey sir





Can AI help in navigating mental health?

How can natural language processing programmes offer personalised and immediate care? How can bias be mitigated in these chatbots? Do they help clinicians as well?

PULSE-CHECK

<u>Iti Bhargava</u> <u>Manmath Goel</u> <u>Namrata Rao</u>

The story so far:

therapy is a text away. Natural language processing (NLP), a branch of Artificial Intelligence (A), enables computers to understand and interpret human language that mirrors human comprehension. In mental healthcare, we are already seeing a rapid evolution of use cases for Al with affordable access to therapy and better support for clinicians.

How does it help patients? External and internalised stigma persists across demographics and countries. Through text-based platforms and virtual mental health assistants, NLP programs provide privacy and anonymity that can improve help-seeking behaviour. For users, the chatbot can support them in reframing thoughts, validating emotions and providing personalised care, especially in the absence of human support. Not only is this beneficial when a therapist is not accessible, but it also helps improve patient health outcomes just as well as in-person care. Mental health treatment requires continuity of care to take a more holistic approach and reduce instances of relapse. For example, digital therapy assistants can help point you to resources for healthier coping in instances of distress, grief, and anxiety. Since these chatbots are scalable, cost-effective, and available 24x7, they could therefore be integrated into existing health programs. Additionally, companies building chatbots must proactively expand the scope of service delivery

through partnerships and collaborations for follow-up services such as referrals, in-person treatment, or hospital care, where needed.

How does it help clinicians? Mental health illnesses have complex causes of origin, making it difficult to design a straightforward protocol or make a quick and accurate diagnosis. By using vast datasets, Al tools can help summarise information including clinical notes, patient conversations, neuroimages, and genetic information. This can help clinicians get up to speed with the entire patient history, saving valuable time during sessions.

Recent advancements in NLP programs have demonstrated the ability to forecast responses to antidepressants and antipsychotic drugs by analysing brain electrical activity, neuroimages, and clinical surveys. Such predictive capability can streamline treatment decisions and minimise the risk of ineffective interventions. Some chatbots are also creating e-triaging systems that can significantly reduce wait time and free up valuable clinical person-hours. With improving bandwidth, mental health providers can devote a higher proportion of time to severe mental illnesses, such as bipolar disorder and schizophrenia, where specialised care is required.

What's next?

There is immense potential and promise in these applications and we expect to see a growing adoption. Going forward, companies must refine these applications by using more diverse population-wide datasets to minimise bias. These programs can also incorporate a wider set of health indicators for a comprehensive patient care experience. We expect greater success of these programs if they are guided by a conceptual framework for improving health outcomes and rigorously and continuously tested.

In the pursuit of innovation, governments and institutions need to prioritise user safety and well-being by ensuring adherence to global compliance standards. As these applications evolve, we must persist in updating our beliefs, governing laws and regulations, and demanding better standards of care.

Iti Bhargava and Namrata Rao are researchers in mental health in India, and Manmath Goel is a healthcare investor.

THE GIST

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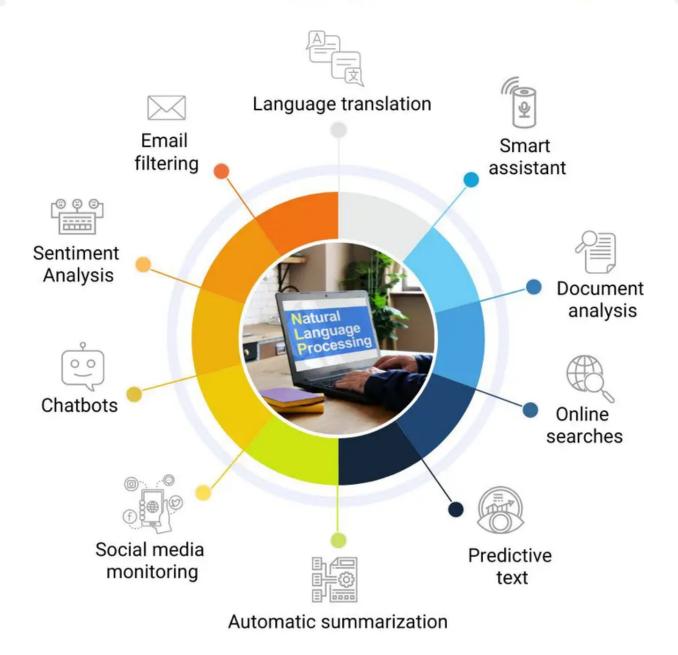


AI FOR MENTAL HEALTH

- We live in a world where therapy is a text away.
- Natural language processing (NLP), a branch of Artificial Intelligence (AI), enables computers to understand and interpret human language that mirrors human comprehension.
- In mental healthcare, we are already seeing a rapid evolution of use cases for AI with affordable access to therapy and better support for clinicians.



Applications of Natural Language Processing





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Drowning the major cause of migrant deaths: UN

Agence France-Presse BERLIN

Drowning had been the biggest cause of recorded migrant deaths over the past 10 years, the UN's migration agency said on Tuesday. Of the 64,000 migrant deaths recorded by the UN's International Organization for Migration (IOM) over the last decade, nearly 60% were linked to drowning.

Of those deaths at sea, over 27,000 occurred in the Mediterranean, a route followed over the years by many migrants trying to reach southern Europe from northern Africa.

The IOM however stressed the figures published in the report were incomplete. Of those recorded, two in three cases remained unidentified. In over half of all cases, the IOM was unable to even establish the sex or age of the migrant. Despite the limits in the data, the IOM had recorded the deaths of "almost 5,500 females" on migration routes and "nearly 3,500" children.

And in cases that could be identified, just over onethird came from "countries in conflict or with large refugee populations".

The figure highlighted "the dangers faced by those attempting to flee conflict zones without safe pathways", it said.

Over 8,500 people died on migration routes worldwide in 2023, making it the deadliest year since the IOM started collecting data a decade ago.

So far in 2024, the figures were "no less alarming", the organisation said.

The hindu analysis by saurabh pandey sir





Drowning major cause of Migrant Death

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UN's International Organization for Migration (IOM)

- Established in 1951, the International Organization for Migration (IOM) is the leading intergovernmental organization in the field of migration and is committed to the principle that humane and orderly migration benefits migrants and society. IOM is part of the United Nations system, as a related organization.
- IOM supports migrants across the world, developing effective responses to the shifting dynamics of migration and, as such, is a key source of advice on migration policy and practice.





- The organization works in emergency situations, developing the resilience of all people on the move, and particularly those in situations of vulnerability, as well as building capacity within governments to manage all forms and impacts of mobility.
- The Organization is guided by the principles enshrined in the Charter of the United Nations, including upholding human rights for all.
- Respect for the rights, dignity and well-being of migrants remains paramount.



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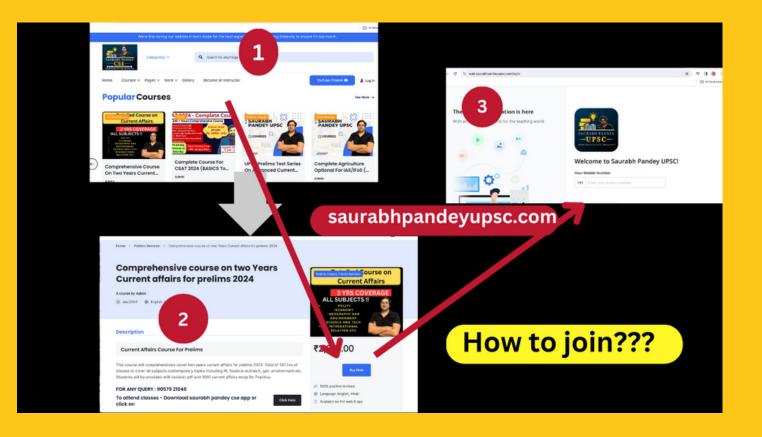


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