

Context of mental health data in India

Mental health in India

According to the Global Burden of Disease study, one in seven Indians were affected by mental disorders of varying severity in 2017 (197.3 million people, including 45.7 million with depressive disorders and 44.9 million with anxiety disorders)¹. However, there is little capacity to support those experiencing mental health problems since there is a shortage of mental health specialists (0.3 psychiatrists, 0.07 psychologists and 0.07 social workers per 100,000 population²), there's limited access to mental health services and stigma associated with poor mental health, meaning that only 10-12% of people experiencing mental health problems will seek help³.

Numerous political initiatives have been taken by the government, such as the first Mental Health Policy 2014⁴ and passing the Mental Healthcare Act 2017 (the first time in Indian history that attempted suicide was decriminalised)⁵. These legislations provide high-level direction for ensuring mental health promotion, resourcing, prevention and treatment services, although they will inevitably have some limitations⁶. On the practical approach, the Indian government also created additional capacity by establishing centres of excellence that emphasised community-based mental healthcare and expanded the District Mental Health Programmes (DMHP) under the National Mental Health Programme (NMHP)⁷.

These initiatives demonstrate the public health need for mental health improvement in India, and where there is public health infrastructure (such as the DMHPs), there is likely to be data associated with it at the local and national levels for operational, research and evaluation purposes. But, whilst mental health is being approached from political and practical agendas, the concept of poor mental health has cultural dimensions that are likely to skew the data – the stigma associated with mental health will hinder anyone seeking help, thus limiting opportunities for meaningful data collection. For example, in Urdu while there are terms for sadness (*udaasi*), grief (*shok*) or devastation (*bejasi*) and other Indian languages, the specific terminology to address different mental illnesses is lacking⁸. The World Economic Forum recently commissioned The Live Love Laugh Foundation to research how India sees mental health, resulting in some harrowing statistics such as whilst awareness of mental illness of high (87% of the respondents were aware) 71% described people with mental health problems with terms associated with stigma such as “crazy, mad, stupid, irresponsible or careless”⁹.

Below lists some possible data sources, organisations (who may be owners of mental health data and/or are potential partner organisations for a mental health data challenge), and a brief insight into the regulatory landscape.

Data sources

Electronic health records (EHR) landscape in India

The level of EHRs and/or ICT use in health facilities is very mixed across India, with private sector hospitals in the process of implementing EHRs as well as both the Central Government and State Governments. Generally, there is little interoperability or sharing of data between health facilities and there is no unified

¹ <https://www.thelancet.com/action/showPdf?pii=S2215-0366%2819%2930475-4>

² http://origin.searo.who.int/india/topics/mental_health/about_mentalhealth/en/

³ <https://www.weforum.org/agenda/2018/04/5-charts-that-reveal-how-india-sees-mental-health/>

⁴ National Mental Health Policy of India 2014 https://nhm.gov.in/images/pdf/National_Health_Mental_Policy.pdf

⁵ <https://www.prsindia.org/uploads/media/Mental%20Health/Mental%20Healthcare%20Act,%202017.pdf>

⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7114045/>

⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6102961/>

⁸ <https://edition.cnn.com/2020/09/06/india/india-mental-health-dst-intl-hnk/index.html>

⁹ <https://www.weforum.org/agenda/2018/04/5-charts-that-reveal-how-india-sees-mental-health/>

EHR system at the moment¹⁰. It is also unclear whether EHRs would be a potential data source for mental health data. Nevertheless, the government have proposed a number of digital health and electronic health record initiatives including:

- Electronic Health Record Standards for India in 2013¹¹
- the National eHealth Authority (NeHA) established in 2015¹²
- the National Health Portal launched in 2016¹³
- the National Health Stack in 2018¹⁴
- the National Digital Health Blueprint in 2019¹⁵

In 2018, the National Health Stack was announced by the National Institution for Transforming India (NITI Aayog). It proposed a visionary digital framework aiming to create digital health records for all the citizens of India by the year 2022. It represents a holistic platform that supports and integrates health IT solutions, enabling a central place for EHRs, insurance claims, analytics, and patient data access, and should it be successful, it could be the main source of health data in the form of EHRs going forward.

However, concerns have been raised regarding the National Health Stack, for example:

- *Consent to data sharing:* The National Health Stack relies upon 'India Stack'¹⁶, an ambitious and controversial project for creating a unified software platform for citizen's data. However, it allows data to "move freely and securely to democratize the market for data", so concerns were raised that, with over 1.2bn Indians coming into this framework, there will be many who are not aware what they are giving consent to¹⁷.
- *Linkage to other data:* The data is also reliant upon the Aadhaar unique ID system which has had a number of violations to individual privacy (leaks of government databases, data is linked to companies for commercial purposes such as Amazon, phone companies, internet providers, Uber) leading to a Supreme Court ruling in 2018 stating that Aadhaar couldn't be made mandatory due to citizens' Right to Privacy¹⁸. There have been cases where people were refused treatment by not providing an Aadhaar ID at hospitals when they wanted to keep their health data private (e.g. HIV-positive patients were denied treatment if they didn't link their Aadhaar ID to health records for fear that their families might find out)^{19,20}.
- *Data quality:* There's a high risk of poor quality data since hospitals in India are already severely understaffed – who is going to input, sort and clean the data? There are also no incentives or accountability structures to ensure that data is entered and updated accurately²¹.

Due to some of the concerns, the MoHFW decided the National Health Stack needed further examination and so prepared a new report called the National Digital Health Blueprint in 2019 which may be more comprehensive (although we'd need to look more thoroughly through the document)²².

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5116537/> ,
https://csd.columbia.edu/sites/default/files/content/docs/ICT%20India/Papers/ICT_India_Working_Paper_25.pdf

¹¹ <https://main.mohfw.gov.in/sites/default/files/17739294021483341357.pdf>

¹² https://www.nhp.gov.in/national_eHealth_authority_neha_mt1

¹³ <https://www.nhp.gov.in/>

¹⁴ https://niti.gov.in/writereaddata/files/document_publication/NHS-Strategy-and-Approach-Documents-for-consultation.pdf

¹⁵ https://www.nhp.gov.in/NHPfiles/National_Digital_Health_Blueprint_Report_comments_invited.pdf ,

<https://main.mohfw.gov.in/newshighlights/final-report-national-digital-health-blueprint-ndhb>

¹⁶ <https://www.indiastack.org/>

¹⁷ Accenture report: Future of Patient Data <https://www.accenture.com/fi-en/insights/industry-x-0/future-patient-data>

¹⁸ <https://www.theguardian.com/world/2018/sep/26/indian-court-upholds-legality-of-worlds-largest-biometric-database>

¹⁹ https://pathwayscommission.bsg.ox.ac.uk/sites/default/files/2019-09/lessons_from_aadhaar.pdf

²⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7133485/>

²¹ <https://cis-india.org/internet-governance/blog/bloomberg-quint-murali-neelakantan-swaraj-barooah-swagam-dasgupta-torsha-sarkar-august-14-2018-national-health-stack-data-for-datas-sake-a-manmade-health-hazard>

²² https://www.nhp.gov.in/NHPfiles/National_Digital_Health_Blueprint_Report_comments_invited.pdf

Given the stigma associated with mental health, the limited access to professional help (meaning few people are able to get public or private treatment) and concerns regarding the National Health Stack, it is unlikely that there will be one single EHR data source available for running a challenge at the moment, but region or hospital-specific EHR data may be available (further investigation would be needed).

Other government-led data sources

Open Government Data (OGD) Platform India²³ :

- OGD is a platform for organisations to publish datasets for public use. It includes a wide range of datasets, from 174 departments, including on mental health and health services. We'll need to do a proper dig around to see what data is there and assess its usefulness/quality, but it could be linked to other datasets (e.g. OpenStreetMap for geospatial data). For example, some of the suicide data has been used for a Kaggle challenge (data science competition)²⁴

National Mental Health Survey of India²⁵ :

- The government commissioned NIMHANS (National Institute of Mental Health and Neurosciences) to undertake a survey to develop data on prevalence, pattern and outcomes for mental disorders. The 2015-2016 survey covered 39,532 individuals from 12 states, and the data is available on GHDX (IHME)²⁶

Apps and telemedicine as a data source

India has 877 million wireless technology subscribers (of which 96% are phone users). This offers a great opportunity for telemedicine or mobile Health (mHealth) focused on mental health, for example through apps.

Mental health apps tend to be one of 3 types, all of which may have a large amount of data collected: (1) communication with family, caregivers or other form of social support, (2) extension off traditional in-person therapy such as symptom tracking, self-monitoring, and (3) smart apps that automatically predict relapse, worsened symptoms or changed activity²⁷.

One example of a mental health app developed in India (and now has a global reach expanding to users in the USA and UK) is 'Wysa' developed by Touchkin²⁸. The chatbot, Wysa, collects data from mobile phones and sensors, and uses machine learning to identify potential mental health problems in patients through changes in their activity, sleep, and communication patterns. The app will also notify the user if they are at risk of depression²⁹. In 2019, Wellcome partnered with the BBC to organise an event where members of the Oxford Neuroscience, Ethics and Society Young People's Advisory Group (NeurOx YPAG) participated in a session about mental health chatbots (including Wysa) which resulted in a BBC Tomorrow's World video clip titled "Would you trust a chatbot therapist?"³⁰.

There are also more people contacting medical services via phone calls (like we have NHS 111 in the UK) which is likely to collect patient data. For example, the Direct Intervention System for Health Awareness³¹ based in Kerala provides support and directs patients to the District Mental Health Programme, and at the start of the Covid-19 pandemic in March and April 2020, they received 4,000 calls per day mostly relating to mental health³².

²³ <https://data.gov.in/>

²⁴ <https://www.kaggle.com/rajanand/suicides-in-india>

²⁵ <http://indianmhs.nimhans.ac.in/Docs/Summary.pdf>

²⁶ <http://ghdx.healthdata.org/record/india-national-mental-health-survey-2015-2016>

²⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4683818/>

²⁸ <https://www.wysa.io/>

²⁹ <https://cis-india.org/internet-governance/ai-and-healthcare-report>

³⁰ <https://www.youtube.com/watch?v=1ayTEoFEgyE> , <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6286427/> , <https://journals.sagepub.com/doi/10.1177/1178222619829083>

³¹ <https://disha1056.com/>

³² https://apolitical.co/en/solution_article/how-one-indian-state-is-combatting-covid-19s-mental-health-effects

Other data sources

- Research data e.g. Global Burden of Disease, NIMHANS, George Institute (see below under Organisations)
- Pharmaceutical data e.g. IQVIA³³ – unclear what mental health data they have but it is a world leader in using data, technology, advanced analytics and human expertise to help customers drive healthcare and human health.

Organisations

Non-governmental organisations

- The Mental Health Innovation Network³⁴
 - A global community of mental health innovators (established by LSHTM and WHO). Many of these innovations will collect data, or will be associated with organisations which do, and therefore could be a potential data source. Their strength would be the on-the-ground, local knowledge and approach to improving mental health (and may prove to be a good network of potential teams to participate in the challenge). One example innovation is the Programme for Improving Mental Health Care (PRIME)³⁵ which aims to create high quality research evidence on how best to implement and expand coverage of mental health treatment programmes in low resource settings. Access to PRIME's data is available through Stanford Population Health Sciences³⁶
- Tata Trusts:
 - They were working to map and understand the current data landscape (with Stanford School of Medicine's Population Health Sciences India Centre), although it's not clear where this project has got to. They have a number of data and digital related projects (e.g. focusing on digital literacy³⁷) and are also supporting IT/digital projects around India including one with the Nagpur District Mental Health Program.
- PATH:
 - PATH work in India (as well as other LMICs) and have projects on digital health / data in globally³⁸. They are at the forefront of enabling digital transformation in India by supporting the development and implementation of digital tools across public health programs. They have an Impact Lab which supports the 'lab to market' journey of innovators (established with Tata Trusts)³⁹. They also bring governments, non-profits, private sector, regulatory bodies and international organizations together for such innovations to be adopted by health systems locally and globally.
 - They may not have projects and/or data related to mental health specifically at the moment (according to their website) but they do have a local, national and global understanding of digital and data-driven health initiatives.
- The Centre for Internet and Society, India
 - See their report on AI in the Healthcare industry in India⁴⁰ for examples of AI and tech organisations and tools, as well as an overview on the policy, regulatory, legal, cultural landscapes.

³³ iqvia.com/locations/india

³⁴ <https://www.mhinnovation.net/>

³⁵ <https://www.mhinnovation.net/innovations/prime-india>

³⁶ <https://redivis.com/StanfordPHS/datasets/1210>

³⁷ <https://www.tatatrusts.org/our-work/digital-transformation/digital-literacy>

³⁸ <https://www.path.org/digital-health/?countrypage=india&sort=date> , <https://www.path.org/where-we-work/india/>

³⁹ <https://www.path.org/media-center/tata-trusts-and-path-announce-indias-first-impact-lab-for-public-health/>

⁴⁰ <https://cis-india.org/internet-governance/ai-and-healthcare-report>

Research organisations

- NIMHANS (National Institute of Mental Health and Neurosciences)⁴¹
 - NIMHANS is a multidisciplinary institute for patient care and academic pursuit in the field of mental health and neurosciences. They're likely to have research projects with substantial amounts of data, so could be a partner in running the challenge or a data provider.
- George Institute for Global Health⁴²
 - A leading independent medical research institute (which is also based in Australia, China and the UK). They focus on the use of innovative approaches to prevent and treat the common causes of premature death and disability, and promoting equity in health.
 - Example project: SMART Mental Health program—a digital mental health application for screening, management, referral and treatment of depression, stress and suicidal risk in rural patients through primary health center in Andhra Pradesh revealed positive treatment outcomes.⁴³
- DBT/Wellcome Trust India Alliance (India Alliance)
 - According to the ODI's scoping report for the Global Health Data Challenges, the India Alliance has a history of running health related challenges and grants in India. They may be a useful organisation to consult in the set-up of a challenge (and may know the mental health data landscape), given the relationship with Wellcome.
- Biotechnology Industry Research Assistance Council (BIRAC)⁴⁴
 - BIRAC is a not-for-profit set up by Department of Biotechnology (DBT), Government of India as an Interface Agency to strengthen and empower the emerging Biotech enterprise to undertake strategic research and innovation, addressing nationally relevant product development needs
 - As well as working with Nesta for their Longitude prize (focused on AMR)⁴⁵, they have also worked with Grand Challenges Explorations (India) to provide 18-month grants for various projects, one of which focuses on mental health (awarded in August 2017 to Sequoia Insilico for a study aiming to develop a tool that would support mental health professionals)⁴⁶.

Legal & regulatory landscape

- National e-Health Authority⁴⁷: The goal of NeHA was to ensure development and promotion of e-Health ecosystem in India for enabling, organizing, managing and providing effective people-centred health services to all in an efficient, cost-effective and transparent manner.
- Aapti Institute were commissioned by ODI to do a legal and regulatory landscape for India (focused on snakebites, but should be applicable to mental health too – this is available in the ODI scoping report document)
- Also see the Centre for Internet and Society report which includes information on the policy and regulatory landscape for AI in healthcare⁴⁸.

⁴¹ <https://nimhans.ac.in>

⁴² <https://www.georgeinstitute.org.in/>

⁴³ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0164404>

⁴⁴ <https://birac.nic.in/index.php>

⁴⁵ https://birac.nic.in/desc_new.php?id=273

⁴⁶ <https://birac.nic.in/grandchallengesindia/program.php?pid=6>

⁴⁷ <http://nhp.org.in/bn/e-health-intiatives?start=5> , <https://www.investindia.gov.in/team-india-blogs/importance-national-e-health-authority-neha-during-covid-19>

⁴⁸ <https://cis-india.org/internet-governance/ai-and-healthcare-repor>