Mental health data and where to find it



### MENTAL HEALTH DATA AND WHERE TO FIND IT

## **INTRODUCTION**

This policy brief summarises and signposts the main sources of mental health-related data for users. It outlines the pros and cons of different datasets, identifies current data gaps, and lists the actions required to address them. And it highlights the potential of recent innovations.

Having timely, representative, good-quality data on mental health is essential to provide an evidence base for decision-making, drive policy change, ensure accountability, and make the case for increased investment and improved access to services. United for Global Mental Health (UnitedGMH) and many of our national partners are already using data to support successful advocacy, as the examples in the following boxes 1-3 illustrate.

## Integrating mental health into the Global Fund's HIV and TB programming

There is a clear bi-directional relationship between HIV/TB and mental ill health, with each being a risk factor for the other. UnitedGMH understood that for policymakers to increase the integration of mental health services into HIV and TB programmes, they needed evidence of the potential impact and what it would cost. <u>UnitedGMH's policy brief Bending the Curve</u>: The impact of integrating mental health services on HIV and TB outcomes presented new research based on data projections to quantify the benefits of integration. The headline results estimated integrating mental health had the programmes could speed up the reduction in infections by 10-17% for HIV and 13-20% for TB. This would mean almost one million people could avoid contracting HIV – the same number of total infections that is currently predicted for 2026 – and as many as 14 million TB infections could be avoided, all by 2030. UnitedGMH and its partners used this research to help persuade the Global Fund to fight AIDS, TB, and Malaria to include mental health in its 2023-2025 strategy, and in national HIV and TB programmes in over 30 countries.

### Decriminalising suicide in Ghana

Until recently, Ghana was one of around 20 countries where attempted suicide remains a crime. Criminalising suicide does not prevent people from acting on suicidal thoughts, it simply deters them from seeking help at times of crisis. That makes criminalisation a significant barrier to effective suicide prevention measures. So in 2012, vigorous efforts began in Ghana to decriminalise suicide. An initial petition to parliament failed to gain traction as it lacked context-specific evidence to support its case. So a collaborative effort led by the Association for Suicide Prevention Ghana (GASP) and the Centre for Suicide and Violence Research (CSVR) in Accra gathered substantial local data and evidence about the impact of the current law. They then presented their findings to key stakeholders - e.g. lawyers, judges, MPs, traditional leaders, police, school staff, media professionals and religious leaders - both face-to-face and via training events. When a second petition was presented in 2017, parliamentarians, shocked by the data and evidence presented, began to engage with the issue. In 2021, an MP who had lost a daughter to suicide led a team of MPs (in collaboration with GASP and CSVR) to table a private member's bill on decriminalisation. Finally, on 28 March 2023, Ghana's parliament approved amendments to the Criminal Offences Act of 1960, which previously made attempted suicide a criminal offence. When this receives presidential assent, people who attempt suicide will no longer face jail terms or hefty fines under the law - they will be regarded as people who need mental health support.

### The new Mental Health Act in Nigeria

Recent decades have seen multiple failed attempts to overturn Nigeria's 1958 Lunacy Act, a colonial legacy which continued to guide the country's mental health services for 64 years. Concerted efforts by professional associations and civil-society organisations were met with a lack of understanding and an absence of political will. But then came a renewed attempt to overturn the legislation during the 8th National Assembly (2015-2019). This time, advocates used data to support their case. They presented legislators with information on the number of people in Nigeria with mental health conditions, the level of absenteeism in the workplace as a result, and the impact on families because of out-of-pocket expenditure. Over time, they raised awareness and galvanised action. They secured the support of Senator Dr Ibrahim Yahaya Oloriegbe and the Honourable Dr Yusuf Tanko Sununu - the Chairs of the Senate Committee on Health and the House of Representatives Committee on Health Institutions respectively. Both are medical doctors with key positions at the National Assembly and vast experience of humanitarian and development work in Nigeria. A new Mental Health Act was finally passed by the 9th National Assembly and signed by the President in January 2023, consigning the 1958 Lunacy Act to history. The new Act established key human rights protections for people with mental health conditions, an expansion of community-based mental health services and the creation of a Mental Health Department at the Federal Ministry of Health

## THE OVERALL STATE OF MENTAL **HEALTH DATA**

There are rising concerns about mental health across the world following the COVID-19 pandemic. The World Health Organisation (WHO) estimates that the first year of the pandemic triggered a 25% increase in depression and anxiety worldwide, with women, young people, and those with pre-existing physical health conditions worst affected.<sup>1</sup>

Against this background, the scale of current data gaps on mental health, especially in low- and middle-income countries (LMICs), has been exposed and become an increasing cause for concern. UnitedGMH is a partner in Countdown Global Mental Health 2030 - an initiative that aims to provide an overall monitoring framework on global mental health and a coherent set of indicators for measuring progress. Countdown's interactive dashboard makes the latest mental health data accessible, and this includes the total number of missing data points for each country. The 2023 monitoring report notes that over half of countries are unable to confirm how much they spend on mental health,<sup>2</sup> and over 60% of countries have not published a specific report on mental health based on data during the past two years.<sup>3</sup>

Data on the mental health of children and adolescents is especially scarce. Research shows that mean global coverage of prevalence data for six mental disorders in ages 5-17 years is just 6.7%, and 124 out of 187 countries have no data on any disorder. Coverage is especially low in LMICs, with no region in sub-Saharan Africa having more than 2% prevalence data coverage for any disorder.<sup>4</sup> These 'data deserts' are of particular concern given that 50% of mental disorders have their onset by the age of 14,<sup>5</sup> an estimated one in seven 10-19-year-olds globally live with a mental disorder and suicide is the fourth leading cause of death among 15–19-year-olds.<sup>6</sup>

It should be noted that mental health data is not simply about prevalence estimates and service coverage. Data on the social, economic, and environmental determinants of mental health is vitally important in understanding the underlying causes of mental health conditions. While the policy and legal frameworks for mental health in each country, plus the level of financial and human resources, are directly relevant to mental health outcomes.

- 3 Ibid

4 Erskine H and others (2016) The global coverage of prevalence data for mental disorders in children and adolescents 5 Kessler RC and others (2005). Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Comorbidity Survey Replicatio 6 UNICEF (2021) The State of the World's Children

The following sections outline the main types of mental health data available from official sources (governments as well as and intergovernmental organisations such as the UN) and unofficial sources (e.g. the private sector, civil society organisations and citizengenerated data). The paper then offers recommendations for action.

## **OFFICIAL SOURCES OF MENTAL HEALTH DATA**

## **GOVERNMENT DATA**

National statistics offices (NSOs) are responsible for collecting and collating data and publishing government statistics on a wide range of issues, while data on health services is typically collected via national health systems. What data is collected and published on mental health varies from country to country, depending on the political priority of mental health, the availability of data and the strength of the national statistics system. The UN Statistics Division (UNSD) publishes country profiles of statistics systems which include information on data collection and dissemination. While the World Bank's statistical performance indicators provide a framework for assessing the performance of national statistical systems and efforts to improve them. This heat map shows all too clearly the capacity gap between high-income countries (HICs) and LMICs.

Significant data and analysis on mental health is publicly available in HICs. For example, in March 2023 the UK's Office for National Statistics (ONS) published a summary of its current and future analytical work related to mental health, while the Australian Bureau of Statistics (ABS) Study on Mental Health and Wellbeing regularly publishes and updates statistics on the prevalence and the use of services. In LMICs, where treatment gaps for common mental health conditions such as depression are estimated to be as high as 90%,<sup>7</sup> the situation is very different - much less data exists. The World Health Organisation's Mental Health Atlas collects and publishes data on the availability and reporting of mental health data by national governments (see below for details). The 2020 edition found that a quarter of responding countries in both the low-income and lower-middle-income groups reported no compilation of mental health statistics for the last two years, compared with 8% and 10%, respectively, of upper-middle- and high-income countries. In addition, LMICs frequently have under-funded NSOs, a situation compounded by COVID-19. The UNSD

7 Hanlon C, Thornicroft G and Lund C (2022) Bridging the global mental health gap

<sup>1</sup> WHO news release (March 2022) 2 WHO Mental Health Atlas (2020)

reported that in sub-Saharan Africa during the pandemic, 61% of countries saw the costs of data collection rise, while 71% experienced a drop in government funding and 59% saw a drop in donor funding for NSOs.<sup>8</sup>

The principal sources of national data on mental health include:

## **1. ADMINISTRATIVE DATA**

Administrative data is the data collected when citizens use government-run services such as health, education, and social protection. It provides information based on interactions with individual people, and compiles data from records kept by schools, hospitals, community health workers and other professionals. Having good-quality administrative data on mental health is essential for operational purposes, to plan, manage and monitor services effectively, and improve performance. Personal data is highly sensitive, so maintaining the security and privacy of individuals' data is paramount. But where suitably anonymised data collected via administrative systems is made publicly accessible, it can provide valuable insights about trends in mental health at national and sub-national levels that can be used for research, advocacy, and accountability purposes.

The extent to which mental health data collected via national administrative systems is publicly accessible varies enormously. For example in England, the National Health Service publishes monthly statistics on mental health services, a mental health annual bulletin dashboard, a mental health act annual dashboard and a restrictive interventions monthly dashboard. Clinicians, commissioners and researchers can also request access to the mental health services data set.

In LMICs, the most commonly used health information system is the <u>DHIS2 open source</u> software platform, currently in use by 76 countries. DHIS2 is a global collaboration led by the Health Information System Programme (HISP) at the University of Oslo, with funders including Norad, PEPFAR, UNICEF, WHO, Global Fund, Gavi and the Gates Foundation. As it is released under an open-source licence, the software can be freely used, modified, and shared. But each country maintains its own adapted version of DHIS2 and has full ownership of the application and of the data contained in it. DHIS2 documentation includes a <u>mental health module</u> within the community health information system package; it was added in 2021, with provision for monthly and annual reporting on mental health. It is for individual countries to decide which modules to implement in line with their national priorities. Some, like Uganda, had already customised their DHIS2 system to collect data

8 UN Statistics Division (2022) Thinking beyond crisis: using the pandemic to advance high-quality, timely and inclusive data

on mental health. While national health information systems are potentially a rich source of data, in LMICs, they suffer from two main drawbacks. First, they only collect data from those who seek and/or receive treatment, and both the lack of mental health services and the stigma associated with seeking help means those numbers are low. Second, the data that is collected is often not publicly accessible, although there is growing interest and discussion of this issue within DHIS2's vibrant community of developers and users.

# CIVIL REGISTRATION AND VITAL STATISTICS SYSTEMS

Civil registration and vital statistics (CRVS) systems maintain national records about key events in a person's life – birth, marriage, death – and all are relevant to mental health:

- Birth registration provides proof of legal identity, which is essential for establishing nationality, avoiding statelessness, and confirming age. This in turn can help to protect children from exploitation, for example through child labour, child marriage and underage military recruitment, all of which are recognised determinants of mental health. A birth certificate may also be required to access services such as health, education, social protection, and justice.
- Marriage registration can help protect girls from underage or forced marriages. It
  provides women with legal protection and rights to inheritance, property, and child
  custody. They may be denied these rights if their marriage is contracted under customary,
  rather than national, law. This in turn can lead to them being evicted and plunged into
  poverty.
- Death registration data, including accurate recording of the cause of death, is essential for calculating suicide rates. It can support national suicide prevention strategies by helping to identify, and take action to close down, commonly used methods.

In HICs, having complete CRVS data is taken for granted, and national statistics are published on a regular basis. In the US, for example, <u>provisional data on births and deaths</u> from the National Vital Statistics System is <u>published on a monthly basis</u>. Ensuring legal identity for all, including birth registration, is an SDG target with an associated indicator (SDG 16.9.1) and some countries are making progress against it. For example, <u>India</u> increased birth registration from 82.4% to 92.7% between 2011 and 2019, while death registrations increased from 64.4% to 92%. Globally however, a quarter of all under-under the age of five do not have their birth registered, rising to nearly half of all under-

fives in sub-Saharan Africa.<sup>9</sup> Meanwhile, the WHO reports that only around 80 countries have good enough vital registration data to estimate suicide rates,<sup>10</sup> underlining the need for greater investment in this area. UNSD <u>publishes the coverage of birth and death registration in all countries, with the latest update (April 2023) available to download from its website</u>. Where data is not available from national CRVS systems, UNSD uses data from the two main household surveys: the UNICEF Multiple Indicator Cluster Survey (MICS) and Demographic and Health Survey (DHS) (see below for more details). It also uses WHO data to estimate coverage.

## **NATIONAL CENSUS AND SURVEYS**

Most countries conduct a population and housing census every ten years, collecting, compiling, and publishing demographic, economic and social data on all individuals and households. Census data is vital for designing, implementing, and monitoring policies, and is an important source of disaggregated data. Whether or not it provides any insights on mental health depends on the issues covered in the census questionnaire, and these are determined by each government in line with its national priorities. For example in New Zealand, where the 2023 census is currently being concluded, people were asked "*Whether a disability, long-term condition, or mental health condition limits their ability to carry out activities of daily living.*" Where data on mental health is collected, it should be included in the NSO's statistical summaries and ideally via the sharing of anonymised microdata from the census.<sup>11</sup>

9 UNICEF data (2022) 10 WHO (2021) Fact sheet on Suicide 11 Microdata are small samples of data for whole households and individuals, which include some associated census characteristics but no information that could identify a household or individual.

# THE WASHINGTON GROUP ON DISABILITY STATISTICS

How questions are framed in national censuses and surveys influences the answers people give. The Washington Group on Disability Statistics has developed question sets on disability suitable for inclusion in census and national surveys, with the aim of providing globally comparable data. Some of these are relevant to mental health. The <u>enhanced short set</u> of questions includes two additional questions on each. Where these questions are included, they can provide useful data on depression and anxiety, though whether these mental health conditions should be regarded as a disability is a contentious issue for some people with lived experience. The Group's Mental Health and Psychosocial Disability Work Group is currently testing seven questions that cover the domains of interpersonal interaction and anxiety and depression. Once this testing is completed, recommendations will be make on which questions to add.

Collecting and using disaggregated data from national censuses and surveys (e.g. by when traditional data-collection methods were not possible because of lockdowns These proved effective in generating near real-time data in a fast-moving environment surveys to monitor changes in mental health, for example the US Household Pulse Survey. the COVID-19 pandemic, governments in a number of countries used experimental pulse orphanages, some of whom may be at higher risk of mental health conditions. During example people who are homeless, refugees and those living in prisons, hospitals, or without connectivity. Household surveys exclude those living outside households, for telephone or online, although this carries the obvious disadvantage of excluding those with other methods of data collection. This is especially true when they are conducted via the advantage of being relatively quick, easy to administer and cost-effective compared representative sample of the overall population, or a subset of particular interest have Statistics Canada's Mental Health and Access to Care Survey, 2022. Surveys based on a India, 2015-16, the 2021 Young Adult Fertility and Sexuality Study in the Philippines and national data on mental health, for example the National Mental Health Survey of Governments may also commission periodic or ad hoc surveys that provide valuable

income, sex, age, race, disability) is vital for analysis. It helps to highlight health inequalities

II

and identify demographics with an increased risk of mental health conditions. Ensuring that those living with a mental health condition are included in the data is an important aspect of delivering the <u>Agenda 2030</u> pledge to leave no one behind.

### **RECOMMENDATIONS FOR ACTION**

- Strengthening foundational data systems, including CRVS and administrative data, is a prerequisite for increasing the quantity and improving the quality of data on all aspects of development, including mental health. This requires increased investment by both national governments and by donors, many of whom de-prioritised their funding for core data and statistics activities at the beginning of the pandemic.<sup>12</sup>
- Given rising concerns about mental health, the collection of mental health data should be prioritised by health information systems, for example by the adoption of the community mental health module in countries using the DHIS2 software platform.
- Governments should routinely include questions about mental health in their national census and population surveys. The questions developed by the Washington Group provide a good starting point for the collection of globally comparable national data. Where data on mental health is collected in national censuses, it should be included in the statistical summaries produced. NSOs should also increase their collection and use of disaggregated data in censuses and surveys.
- Provided the security and privacy of personal data can be assured, suitably anonymised data collected via national systems and surveys, as well as anonymised microdata from the national census, should be made publicly accessible to increase both understanding and accountability.
- Use of representative, small-scale, purpose-built surveys should also be considered to fill data gaps at national level.

## DATA COLLECTED AND PREPARED BY INTERNATIONAL ORGANISATIONS

While nationally produced mental health data should be the bedrock for national decisionmaking, data produced by international organisations provides globally comparable data and generates estimates that can help fill data gaps at country level. One of the weaknesses of global datasets is that they often rely on modelled data, and it is sometimes difficult to ascertain which data has been modelled, and what methodology has been used to produce the data.

International organisations that produce mental health data include:

## THE WORLD HEALTH ORGANISATION (WHO)

The WHO is the leading provider of global data on mental health, and custodian of the only SDG indicator that focuses specifically on mental health (SDG 3.4.2 - suicide mortality rate). Its flagship publication, the <u>Mental Health Atlas</u>, monitors progress towards the targets adopted by member states in the <u>Comprehensive WHO Mental Health Action Plan</u> 2013-2030. Data is collected every three years, and the latest edition is the <u>Mental Health Atlas</u> 2020, which summarises the aggregate results. More detailed data on individual countries is available in the associated country profiles. The Mental Health Atlas is a vital resource that provides comprehensive, globally comparable data on burden, governance, finance, human resources, service availability and uptake, and promotion and prevention. Its disadvantages include its reliance on government self-reported data; significant data gaps for some indicators e.g. psychosis, outpatient visits and involuntary admissions; and its lack of timeliness because of the complexity of the data collection and compilation process. (The majority of the data in the current edition was collected pre-COVID-19 and the final results of next edition are not expected until 2025). Additional WHO datasets and estimates relevant to mental health include:

- <u>Global Health Estimates</u> provide the latest available data on death and disability at global, regional, and country levels, disaggregated by age, sex and cause. That makes them a useful source of data on death (including suicide rates) and disability-adjusted life years (DALYS) related to mental and substance-use disorders. Data is drawn from a variety of sources, including national CRVS systems, estimates from WHO technical programmes, UN partners, and the Global Burden of Disease (see below for details). The underlying data is published via <u>WHO's Global Health Observatory</u>.
- <u>The Health Inequality Data Repository</u> contains datasets of disaggregated data on many topics including mental health (in relation to COVID-19) and disability, drawn from a variety of publicly available sources. (Note: The WHO notes that only 50% of countries

12 UN Statistics Division (2022) Thinking beyond crisis: using the pandemic to advance high-quality, timely and inclusive data

have included data disaggregation in their published national health statistics reports). <u>Global Pulse Survey</u> covers the continuity of essential health services, including mental health services, during the COVID-19 pandemic. Data from the third survey, which covered 129 countries, is available via this dashboard.

• <u>WHO MiNDbank</u> is an open platform with an associated <u>database</u> that brings together country and international resources covering mental health, substance abuse, disability, general health, human rights, and development.

The WHO is working on several initiatives to strengthen mental health data. These include the addition of a new mental health module on depression in its <u>STEPwise Approach to</u> <u>NCD Risk Factor Surveillance (STEPS)</u>, which will enable interested countries to obtain population-representative estimates on the prevalence of depression and service uptake. The WHO is also working with UNICEF on the <u>Joint Programme on Mental Health and</u> <u>Psychosocial Well-being and Development of Children and Adolescents</u>. One of its desired outcomes is that: "An increased number of countries are able to generate and use quality data and evidence to inform multisectoral actions on mental health and psychosocial wellbeing and development of children and adolescents."

# INTERNATIONAL HOUSEHOLD SURVEY PROGRAMMES

The three main international household survey programmes are UNICEF's <u>Multiple</u> Indicator Cluster Surveys (MICS), the <u>Demographic and Health Surveys</u> (DHS) Programme led by USAID and the <u>Living Standards Measurement Study</u> (LSMS) developed by the World Bank's Development Research Group.

In LMICS, where there are significant data gaps in national CRVS and administrative systems, these surveys provide important estimates on a wide range of socioeconomic and demographic indicators. The surveys are typically led by the NSO, with technical assistance and funding provided by the survey programmes and their partners. UNICEF includes questions on depression and anxiety developed jointly with the Washington Group's short set of questions on disability functioning, with LSMS scaling up to do so in future, but that short set does not include the questions on depression and anxiety.

So these three survey programmes collect limited data on mental health conditions. They are nevertheless a key source of data on many of the social and economic determinants of

health, including poverty; inequality; maternal, newborn, child and adolescent health; and educational achievement. This year, UNICEF launched <u>Measuring Mental Health Among</u> <u>Adolescents and Young People at Population Level (MMAPP)</u>, a culturally adaptable and clinically validated tool to help close the data gap on the mental health of adolescents and young people. It is being integrated into the current round of MICS, though as with all new modules, its use will initially be optional.

Another recent innovation is the <u>use of high-frequency phone surveys by LSMS</u> to track the response to, and socio-economic impacts of, COVID-19 – as well as of other economic shocks – in seven African countries. As with pulse surveys, these phone surveys have the significant advantage of providing near real-time data in rapidly changing situations. Again, though, they come with the risk of leaving behind people without mobile connectivity. While mobile phone penetration is increasing in sub-Saharan Africa, it is not predicted to reach 50% of the population until 2025.<sup>13</sup>

The main advantages of international household surveys are that they fill current data gaps in LMICs and produce globally comparable estimates. Some recent innovations also increase their relevance to mental health. As they exclude those not living in households and are based on population samples – the accuracy of which depends on having recent, suitably disaggregated census data which may not be available – the data they provide lacks the granularity, inclusiveness, and accuracy available from well-funded, fully-functioning national data systems. Their coverage is limited to LMICs (118 countries for MICs, 90 for DHS and around 40 for LSMS), so they do not provide data on all countries. Timeliness can also be an issue because implementation is phased, and not all countries take part in all rounds, so the most recent data available for a particular country could be over ten years old.

## UNICEF

UNICEF is the leading source of data on children, collecting, compiling and publishing data on a wide range of indicators in its<u>publications</u>, <u>datasets</u>, and<u>data visualisations</u> and <u>dashboards</u>. Early years experiences impact a child's emotional and physical health, and social development throughout life, which can have profound long-term consequences for their mental health. UNICEF provides a valuable source of data on a wide range of socioeconomic determinants including poverty, nutrition, health, early childhood development education, access to water and sanitation, gender equality, migration and displacement, birth registration, child marriage, child labour, and violence against children. <u>The 2021</u>

13 GMSA (2022) The Mobile Economy sub-Saharan Africa

edition of UNICEF's flagship State of the World's Children report focussed on promoting, protecting and caring for children's mental health, so the report itself, and the associated dataset and statistical tables are especially relevant. Adolescent health is an area of particular concern, with UNICEF estimating that one in seven adolescents experience mental disorders.<sup>14</sup> To address huge data gaps for measuring mental health among adolescents and young people at the population level, UNICEF launched the MMAPP initiative, briefly mentioned above. By establishing global indicators and offering guidance for adaptation and implementation, the MMAPP approach promotes standardised data across four key mental health domains: symptoms of anxiety and depression, functional limitations, suicidal thoughts and behaviours, and care-seeking and connectedness. The resulting data collection tool, which is clinically validated, freely accessible, and culturally adaptable, will be initially integrated into UNICEF's MICS (see above) starting in 2023. The MMAPP module can also be used independently across routine data collection efforts, including nationally representative household or school-based surveys.

In addition, UNICEFs Adolescent Health Dashboard includes.<u>Regional</u> and <u>Country Profiles</u> that collate data from several sources on the state of adolescent health. Several data points focus specifically on adolescent mental health and wellbeing, including the state of national mental health policies and plans, disease burden, as well as risk and protective factors that affect adolescents' mental health and wellbeing.

Finally, UNICEF will take over hosting of the Countdown Global Mental Health 2030 dashboard from September 2023. The transition will make the dashboard more user-friendly, with new data visualisations helping users to extract meaningful insights, and identify critical patterns, progress, and data gaps in global mental health.

## **OTHER UN AGENCIES**

Other UN agencies also collect, compile, and publish data relevant to mental health in line with their mandates. For example, the International Labour Organisation (ILO) publishes labour force survey data drawn from NSO national labour force household surveys that provide headline statistics on employment, unemployment (a key determinant of mental health) and working conditions. The frequency of publication varies considerably across countries. The ILO provides a model questionnaire for use by NSOs and has worked with the Washington Group to develop an optional module on disability. which includes sections

14 UNICEF estimates based on IHME's Global Burden of Disease 2019, as presented in the State of the World's Children report, 2021

on disability identification, barriers to employment, accommodation, attitudes and social protection. <u>ILOSTAT</u> publishes a specific database on <u>disability labour market indicators</u>.

People affected by humanitarian crises, including refugees, may face increased risk of mental health conditions, including depression, anxiety and PTSD.<sup>15</sup> The <u>UN Refugee</u> Agency, <u>UNHCR</u>, maintains a <u>refugee population statistics database</u> while its 2022 annual report on strengthening mental health and psychosocial support (MHPSS) notes that health facilities in 21 countries used UNHCR's integrated refugee health information system (iRHIS) to report on a total of 146,166 consultations for mental, neurological and substance-use conditions. The <u>iRHISdatabase</u> can be accessed by clinicians and researchers on request. Meanwhile, the <u>UN Office for the Coordination of Humanitarian Affairs (OCHA)</u> runs <u>ReliefWeb Response</u>, a digital service that provides data and information about the humanitarian response to individual crises. And OCHA's MHPSS Technical Working Group publishes specific information and data on mental health, for example <u>this overview of services in Ukraine</u>.

The work of the <u>UN Population Fund (UNEPA)</u> covers many of the determinants of mental health. It maintains a <u>world population dashboard</u> that provides data by country and by indicator on issues including population, sexual and reproductive rights, family planning, gender equality, education and labour.

Meanwhile, <u>UNESCO's Institute for Statistics (UIS Stat)</u> is the official source of internationally comparable data on education – another key determinant of mental health.

## WORLD BANK

The World Bank is a major source of data for development. It provides an extensive range of publicly accessible resources, many of which relate to the determinants of mental health. These include:

- the <u>Poverty and Inequality Platform (PIP)</u>, which provides globally comparable estimates on poverty and inequality for over 160 countries
- the <u>World Development Indicators</u>, with a database of 1,400 time-series indicators for 217 countries
- Healthstats, a comprehensive database on health, nutrition, and population
- <u>Health Equity and Financial Protection Indicators</u>, which explore the extent to which countries can deliver Universal Health Coverage without causing financial hardship.

15 WHO (2022) Refugee and Migrant Health Factsheet

- Educational Attainment and Enrolment around the World
- the <u>Human Capital Index</u> (HCl), which measures the amount of human capital that a child born today can expect to attain by age 18, given the risks of poor health and poor education that prevail in the country where she lives
- the <u>Utilisation-Adjusted Human Capital Index (HCI)</u>, which adjusts the HCI for labour market under-utilisation of human capital because of unemployment or lack of relevant skills.

While many of the indicators included in these resources are *relevant* to mental health, few are *specific* to mental health. This reflects the lack of mental health data collected by international household surveys, one of the main sources of data.

The World Bank is currently developing a new mental health strategy. Given the increased prominence of mental health – especially that of adolescents and young people – since the COVID-19 pandemic, this will hopefully see the World Bank increase its collection and use of mental health data.

## ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT (OECD)

The OECD collects, collates and publishes data on a number of indicators relevant to mental health across its <u>38 members</u>. Its annual <u>Health at a Glance</u> report includes indicators on health status, risk factors, access to and quality of care, capacity and resources, and COVID-19. The 2021 report includes a specific section on mental health, with national estimates on depression, anxiety, and death by suicide. The <u>OECD Mental</u> <u>Health Performance Framework</u> was developed in response to a request from OECD health ministers and <u>a new benchmark for mental health systems</u> was published in 2021. It included data on a set of 23 indicators to measure the performance of mental health systems across the OECD. Meanwhile <u>PARIS</u>, the <u>OECD'spatient-reported indicator surveys</u> initiative, seeks to develop, standardise, and implement indicators that monitor patient outcomes and experience of healthcare. The OECD has made a significant investment in mental health and provides high-quality data not available from other sources, but with the obvious limitation of only covering OECD members.

## **RECOMMENDATIONS FOR ACTION**

 To maximise the utility of the WHO's Mental Health Atlas, government focal points should be encouraged to complete the next survey questionnaire (to be launched in 2024) as comprehensively as possible to minimise data gaps, consulting colleagues in other departments as necessary. A process that includes national civil-society organisations and mental health advocates would further

enhance the quality of the data collected, as well as introducing a useful element of external accountability.

- Standardised questions on mental health should be routinely incorporated into the main international household surveys. The Washington Group's work is a good starting point for the collection of globally comparable data.
- Governments participating in the current round of UNICEF MICS (<u>MICS7</u>) should include the optional MMAPP module as a way of addressing current data gaps on the mental health of adolescents and young people. The module should also be incorporated by DHS and LSMS.
- The World Bank should use the opportunity of developing its new mental health strategy to increase its collection and use of mental health data. For example, it could introduce mental health indicators in some of its key initiatives and datasets, such as the Human Capital Index.
- All global data producers who use modelled data should be transparent about its use, and publish their methodologies.

# **NON-OFFICIAL SOURCES OF MENTAL HEALTH DATA**

The last two decades have seen a massive increase in the amount of data available from unofficial sources. There is growing interest in using these to fill data gaps, especially for hard-to-reach groups and individuals. There has also been increasing acceptance of the value of these unofficial sources. The <u>Cape Town Action Plan for Sustainable Development</u> <u>Data agreed at the first World Data Forum in 2017</u> was explicit about the need for both global and national statistics systems to adapt and modernise, working "*in closer partnership with stakeholders from academia, civil society, the private sector, and the public at large*" as well as embracing new technologies and data sources. Many of these sources are now providing useful data on mental health, with a few examples given below.

## ACADEMIA

Academic institutions are a valuable source of mental health data. One of the best-known examples is the work of the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. Its flagship publication, the <u>Global Burden of Disease</u>\_provides a comprehensive picture of mortality and disability across countries, time, age, and sex. It includes data on death by suicide and as a result of substance use, plus estimates on disability-adjusted life years (DALYS), including those attributable to mental disorders,

with <u>country profiles</u> available. IHME also publishes estimates on <u>global expected health</u> <u>spending 2020-2050</u>, <u>global health spending 1995-2019</u> and the <u>development assistance</u> for health database. <u>IHME's Global Health Data Exchange (GHDx)</u> provides free access to its own datasets, and a comprehensive catalogue of surveys, censuses, vital statistics, plus other health-related data. IHME uses heavily modelled estimates which have the advantage of filling data gaps and producing complete datasets, but with the disadvantage that the resulting data is less reliable.

Another example is the <u>World Mental Health Survey Initiative</u>, a collaboration between academics in 30 countries. It seeks to compile cross-national information about the prevalence of and relationships between mental, substance-use and behavioural disorders, based on epidemiological surveys. Epidemiological surveys like this, along with IHME's regularly updated data sets, are especially useful for building up more accurate estimates of the prevalence (including treated prevalence) over time.

Academic research can also be useful in filling mental health data gaps on specific issues, countries and/or target groups. For example, <u>national adolescent mental health surveys</u>, coordinated by the University of Queensland and led by national partners, have been conducted in Kenya, Vietnam and Indonesia. Studies like this provide hugely valuable national data, but in a limited number of countries.

Academic data sources can add value on mental health, but individual studies suffer from a lack of standardisation, which limits their comparability and utility. <u>Members of the</u> <u>International Alliance of Mental Health Research Funders</u> are collaborating on an initiative to develop <u>common metrics in mental health research</u>. They have already identified and agreed measures for child and adult depression and anxiety, and adult functioning, and are working on further areas of research. Increasing coordination and standardisation of mental health research would increase its value for decision-making.

## **OPINION POLLS**

Several global polling companies conduct regular surveys on mental health and wellbeing. For example, <u>Gallup's annual World Poll</u> measures life-satisfaction ratings, with the resulting data used to inform the <u>World Happiness Report</u> produced by the Sustainable Development Solutions Network. The World Poll has been running since 2012, and typically includes a representative sample of around 1,000 people in each of 130 countries, including countries in all regions and income groups. Its results are based on a three-year average. Telephone surveys are used in countries with at least 80% telephone coverage, with faceto-face interviews elsewhere. The latest poll shows that most populations have been

> resilient in the face of overlapping crises, with global life satisfaction averages remaining as high during 2020-2022 as they were before the pandemic. People tend to be happier in countries where the happiness gap is smaller, and the effectiveness of government has a huge impact on people's happiness.

Meanwhile, the annual <u>IPSOS Global Trends Report</u> includes data on attitudes to mental health, covers a smaller number of countries (50 – mainly HIC and UMICs), and is mainly conducted online. In countries with low internet penetration, face-to-face interviews are used. This poll confirms that people increasingly see mental health as being as important as physical health. Although this view is more prevalent in wealthier countries, with people in less well-off countries having to focus on their physical health.

Many non-profit organisations also conduct or commission opinion polls. For example, the annual <u>Mental State of the World Report</u> produced by Sapien Labs is based on data from an online survey of over 400,00 people in 64 countries, drawn from all regions and income groups. It provides an overview on the wellbeing of the internet-enabled population. Meanwhile, McKinsey Health Institute has recently published its <u>2022 Global Gen Z Survey</u>, which surveyed 42,000 respondents in 26 countries (largely HICs and UMICs) on the four dimensions of health: mental, physical, social and spiritual. Both surveys highlight that Gen Z struggle with their mental health more than previous generations, with the Mental State of the World Report noting that this *"represents a sharp reversal of patterns documented prior to 2010, indicating a dramatic decline in mental wellbeing with each younger generation rather than an increase in wellbeing as we age."* 

Well-designed opinion polls can help to fill current gaps in mental health data from official sources. One-off polls can be used to provide timely data on topical issues, while longitudinal studies can identify trends over time, and track changing attitudes towards mental health. For example, key messages from the polls quoted above are that people around the world increasingly see mental health as being as important as physical health, and the mental health of young people is of growing concern in many countries.

Methodology, including coverage and inclusion, is vitally important. Polls that rely solely on telephone or online data collection risk excluding marginalised groups and individuals, while global conclusions cannot be drawn from surveys that cover only a limited number of countries.

# CITIZEN-GENERATED DATA, COMMUNITY DATA AND NGO DATA

Citizen-generated data is data that people, or their organisations produce to monitor services, demand action or drive change on issues that matter to them. It has an important role to play in filling existing data gaps, especially on marginalised groups and individuals, who are frequently overlooked by official data collection exercises.

The collection and use of data produced by and with people with lived experience of mental health conditions is vital in ensuring their views are at the centre of academic and medical research, public debate, and policy decisions. The <u>qualitative and quantitative data</u> collected by the Global Mental Health Peer Network (GMHPN) for the Lancet Commission on ending stigma and discrimination in mental health provides a good example. Of the 300 people from 45 countries surveyed, 90% said that:

 people with lived experience should be treated as well as people with physical health conditions

stigma and discrimination negatively affect most people with mental health conditions
the media could play an important part in reducing stigma and discrimination.

Data from these sources is especially important in terms of reaching marginalised groups and promoting the voice of people with lived experience. As with academic research, the adoption of common standards for data collection and regular collection, rather than one-off surveys, would increase the usefulness of this data.

## **BIG DATA**

Big data refers to the large datasets collected from a wide variety of sources, many of them new, that are too complex to be managed by traditional data-processing software such as customer-transaction data, mobile-phone data and data collected by search engines and social media platforms. Data from these sources can provide useful insights about mental health. For example, amid rising concerns about the impact of climate change on mental health, the Lancet Countdown on health and climate change introduced a new sub-indicator on extreme weather and sentiment based on analysis of Twitter data. It found statistically significant associations between extreme weather events and the number of tweets expressing corresponding positive or negative sentiments. While the data is limited to Twitter users, it nevertheless adds to the data available on this emerging

Research confirms that the <u>use of mental health apps increased during COVID-19</u>. Market data suggests that this trend is likely to continue, <u>with the US market for mental health</u> apps projected to grow by over 15% between 2023 and 2030. Data on mental health app

issue.

usage, and about people's use of crisis helplines, can provide useful information about prevalence and help-seeking behaviour. While mental health apps have the potential to complement traditional therapies and treatment, questions have been raised about their efficacy, with this study finding no convincing evidence to support this. There are also concerns about privacy, with the risk of personal data being shared. <u>A study of 578 mental health apps published in the Journal of the American Medical Association (JAMA) found that while 77% had a privacy policy. 44% shared personal health information with third</u>

In countries with electronic health records – a digital version of patient-centred records that can be instantly accessed by authorised users – big data also includes data collected from hospital and patient records. Where this is routinely collected, it includes data on mental health. Analysing these huge datasets offers significant benefits in terms of patient treatment and care and can inform medical research. But again, such data comes with the challenge of data protection, and the need to ensure that robust systems are in place to govern the collection, sharing and use of sensitive personal data. The other risk is that increasing use of big data in health care, including mental health care, will further fuel the growing digital divide, with the poorest people and countries left behind.

## **ARTIFICIAL INTELLIGENCE (AI)**

The opportunities and risks associated with Al have become a hot topic, including its application to healthcare and medical research. Al chatbots are already being used to provide 24/7 support for people with mental health conditions.

The WHO's report, <u>Ethics and Governance of Artificial Intelligence for Health</u> highlighted some of the potential benefits of AI, including:

- improved speed and accuracy of disease diagnosis and screening
- support for clinical care
- research and drug development
- informing a variety of public health interventions, such as disease surveillance, outbreak response and the management of health systems.

The report suggests that AI could empower patients to take more control of their own health care. It could also help poor countries and communities where patients have limited access to health care workers. The benefits outlined could also result in an increase the collection and use of mental health data.

Nevertheless, the WHO cautions against over-estimating these benefits given the significant risks. These include:

- the diversion of resources away from core investments in universal health coverage
- unethical collection and use of personal data
- risks to patient safety and cybersecurity
- the potential for unregulated Al use to subordinate the rights of patients to the commercial interests of powerful technology companies or government surveillance and social control.

This underlines the need for a cautious approach to the use of AI in healthcare, including mental healthcare.

## **RECOMMENDATIONS FOR ACTION**

- Mental health data from unofficial sources can play a vital role in complementing data from traditional sources and helping to fill current data gaps. This is especially true of people and communities frequently excluded from official data collection exercises. Its promotion and use should be encouraged by all actors.
- The adoption of common metrics for mental health research by funders and researchers would result in greater comparability between individual studies and increase the usefulness of the data.
- Opinion polls are an effective way to fill gaps in official data on mental health, provided care is taken to ensure that coverage, sampling and data collection methods are inclusive.
- While one-off data collection via surveys, polls and research studies can provide useful snapshots and highlight emerging issues, regular, sustained data collection is especially useful for decision-making.
- Big data and AI offer potential benefits for increasing the collection and use of mental health data, but they come with significant risks, underlining the need for a cautious approach.

## **2023 GLOBAL MOMENTS: AN OPPORTUNITY FOR ACTION**

There is renewed interest in data for development more broadly as we approach the mid-point of the SDGs. This provides an opportunity to highlight the need for greater investment in the collection and use of data on mental health. The UN Secretary General's

recently published SDG Progress Report notes that "Access to timely, and high-quality, disaggregated data is essential. It can multiply the efficiency and effectiveness of domestic and development spending, generating a 'data dividend' for SDG implementation."<sup>16</sup> His report notes that spending on data and statistics by many NSOs, as well as by donors, remains low and fell during the COVID-19 pandemic. The report encourages increased use of new data sources while emphasising the need for strong data governance and data protection policies, which are lacking in around half of the least developed countries.

The 'data dividend' referred to above is expected to be the focus of a new initiative linked to three key global moments in September 2023:

- the upcoming G20 Summit in India
- the Africa Climate Action Summit in Kenya
- the SDG Summit, which will take place during the UN General Assembly in New York.

Anticipated outcomes are likely to include a commitment to new national-level data partnerships, a capacity-building network and focus on improved donor coordination to reduce fragmentation and deliver better outcomes. The focus on improving data for development at each of these gatherings provides an opportunity to highlight the need for increased investment in the collection and use of data on mental health. It is an issue that has risen up the political agenda significantly since the SDGs were agreed in 2015.

## CONCLUSION

This policy brief summarises and signposts the main sources of mental health-related data for users. It outlines the pros and cons of different datasets, identifies current data gaps, and lists the actions required to address them. And it highlights the potential of recent innovations.

Good data is essential but as this paper shows, rather than coordinate and improve a few data sets, there is a proliferation of data and surveys. Based on the recommendations of this paper, we would strongly encourage donors to coordinate their investment; governments to prioritise better mental health data collection; and stakeholders to identify and address the "newer" areas with significant data gaps, including the impacts of climate change and the environment on mental health.

16 Report of the UN Secretary General (2023) Progress towards the Sustainable Development Goals: Towards a Rescue Plan for People and Planet

## Quick checklist for using mental health data

The following questions are intended as a quick guide for users to consider when using mental health data to support their work.

- Who produces it?
- Who funds it?
- Why is it collected?
- When was it collected?
- How is it collected?
- Who is included (and who is excluded)?
- What level of disaggregation is available?
- Who uses it?
- What do they use it for?
- What are its limitations



