



No Data *is* Data¹

What existing but untapped disaggregated data tells us about inequalities in vaccination rates within states in the Global South

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At the mid-point of the Sustainable Development Goals period, with just seven years left until 2030 and in order to deliver on the central commitment to ‘Leave No One Behind’, clear data about which groups are at risk of being left furthest behind is essential. This brief assesses the available data regarding childhood routine vaccinations and ethnicity, language and religion. It offers suggestions on the relation between childhood vaccinations and ethnic, linguistic and religious diversity across several countries.

Decision-makers need data and statistics that are precise, timely, disaggregated, relevant, accessible and simple-to-use in order to execute and track the Sustainable Development Goals (SDGs) as well as the transformative promise to ‘Leave No One Behind’. Planning, monitoring and reviewing the 2030 Agenda for Sustainable Development necessitates the gathering, processing, analysis and distribution of a vast quantity of data and statistics at the local, national, regional and global levels by numerous stakeholders. We advise that data accessibility, quality and indicators for minority groups that are categorized by religion, language and ethnicity must be taken into consideration and enhanced in order to properly monitor the implementation of the SDGs and the ‘Leave No One Behind’ campaign. The goal

of this brief is to persuade decision-makers to recognise the gaps of inclusiveness in each of the following categories: planning, information gathering and data distribution to enable the Expanded Programme on Immunisation (EPI), which ensures that children in all countries receive life-saving vaccinations.

Summary

The 2030 Immunisation Agenda envisions a society in which ‘everyone, everywhere and at every age fully benefits from vaccinations for good health and well-being.’ ((WHO, 2021), p. 48). Data is required to guarantee that the commitment to ‘Leave No One Behind’ is upheld. This research reveals that roughly three quarters of household surveys used to gather the relevant data did not provide enough information to allow for disaggregation on three key categories, namely religion, ethnicity and language. In short, data gaps exist in survey preparation, data collection and analysis.

Amongst countries analysed for each category, Angola had the highest difference in language. Indonesia and Madagascar had the greatest difference in religion. Indonesia and Côte d’Ivoire had the biggest difference in ethnicity, while Nepal had the largest difference in caste.

Minorities in 58.6% of the countries included in the SDG database had lower vaccination rates than the majority populations. In some countries, minorities

overall had higher rates of vaccination than the majority population but in the same countries there were often other individual minority groups that have lower rates than average. When country specific vaccination rates from all sampled surveys with available data were combined, minorities has lower rates of that majorities. Language and caste minorities have a higher degree of disparity in vaccination rates than religious and ethnic minorities do.

The disparities in terms of vaccination rates within countries and sub-regions are masked by aggregate data. Data at national level falls short of offering a thorough overview. The authors of this research strongly believe that ethnicity, religion and language should be considered as a basic minimum for disaggregation connected to ‘vaccines for all’ monitoring (SDG Target 3.8). Data must be acquired, and surveys must target potentially disadvantaged groups that are currently invisible in the available statistical data. It is critical that sample sizes for these groups be increased in order to assess efficacy and ensure services that reach all groups and address all potential barrier factors. Policies relating to more and higher quality data collecting must be adopted. For optimum results and data safety and security, National Statistical Offices must be autonomous, authoritative and responsible. Furthermore, data collection, analysis, publication and dissemination must follow human rights principles.

Key Points

- 2021 saw the highest number of missed basic childhood vaccinations since 2009. Data from particularly disadvantaged people can be used to improve care, strategic planning and resource optimisation.
- We found that only 29.8% of all 67 countries with vaccination data and questions on religion, ethnicity and language included questions that collect information needed for disaggregation of religion, ethnicity and language. Furthermore, in only 14% of the total number of surveys were these disaggregated findings actually published. Out of the three minority types listed above, linguistic minorities are least likely to have a meaningful question, a sizeable sample for further analyses and published results.
- The largest difference between majority and minority groups was observed in Angola for language, Indonesia and Madagascar for religion, Indonesia and Côte d'Ivoire for ethnicity and Nepal for caste.
- In 34 (58.6%) of the 58 countries selected for analysis, minorities had lower rates of full basic immunisation than the majority population. While religious and ethnic minorities had modestly lower immunisation rates of 1.8% and 1.4%, respectively, caste-based and linguistic minorities had 5% and 5.9% lower immunisation rates.
- Because current survey statistics lack data for potentially disadvantaged groups, it is difficult to draw conclusions, monitor SDGs and track who, where and why specific groups are falling behind. Within data collection, there must be synchronised equity. Data for all ethnic, religious and linguistic groups must be collected on sufficiently large samples, analysed and publicised.
- To accomplish the LNOB principle, along with rates of vaccinations, it is necessary to look deeper into service availability, vaccine hesitancy and vaccination attitudes.
- Data must be gathered and published for all communities wherever feasible to avoid information suppression, but this must be done in accordance with best practice (including OHCHR's Human Rights-Based Approach to Data).
- National Statistical Offices (NSOs) should be given additional autonomy and authority, and they should be the leaders in ensuring inclusion of disaggregation factors, accountability and compliance with the Human Rights-Based Approach to Data.

Inequalities have been identified between minority populations within a country, including some where minorities had higher overall total immunisation rates. An aerial view of the data has masking effects and aggregated averages overlook important disparities. The Nuristani minority in Afghanistan, for example, has a full basic vaccination rate of 0.7%, despite the fact that ethnic minorities in Afghanistan as a whole have a higher vaccination rate than the national average of 46.3%. As a result, we recommend policymakers, governing bodies and academics to evaluate data by community rather than relying on averages.

Introduction

The World Health Organization (WHO) established the Expanded Programme on Immunisation in 1974 to ensure that all children receive life-saving vaccines, with an initial focus on six childhood vaccine-preventable diseases, namely Tuberculosis, Diphtheria, Tetanus, Pertussis, Poliomyelitis and Measles, and four recommended vaccines (Bacillus Calmette Guerin, DPT, Polio and Measles Containing Vaccine), hereafter referred to as 'Basic Vaccination'. More vaccinations were introduced over

time and each country has its unique immunisation programme.

We analyzed the gaps in equity data and the uptake of the Basic Vaccinations in the most recently reported Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Surveys (MICS) from 71 countries, 48 years after the EPI programme's inception. It is still difficult to quantify the uptake of vaccination of minority and underrepresented communities. We are

No Data is Data

only seven years from the target end date for the 2030 Immunisation Agenda with a vision of 'a world where anyone, everywhere, at every age fully benefits from vaccines for good health and well-being', and it is critical to ensure that the mantra of 'Leave No One Behind' is successfully implemented and that there is enough data to calculate the impact (WHO, 2021). As of 2018, 70% of children that were not vaccinated lived in middle-income countries. In 2021, 25 million children under the age of one did not receive basic vaccines. This is the highest number since 2009, and the number of unvaccinated children increased by 5 million since 2019. One of the key challenges of the programme is to monitor data at sub-national and regional levels to enable

countries to prioritise and adapt operational plans and vaccination strategies to focus on immunisation gaps to 'Leave No One Behind' (*Immunisation Coverage*, 2022).

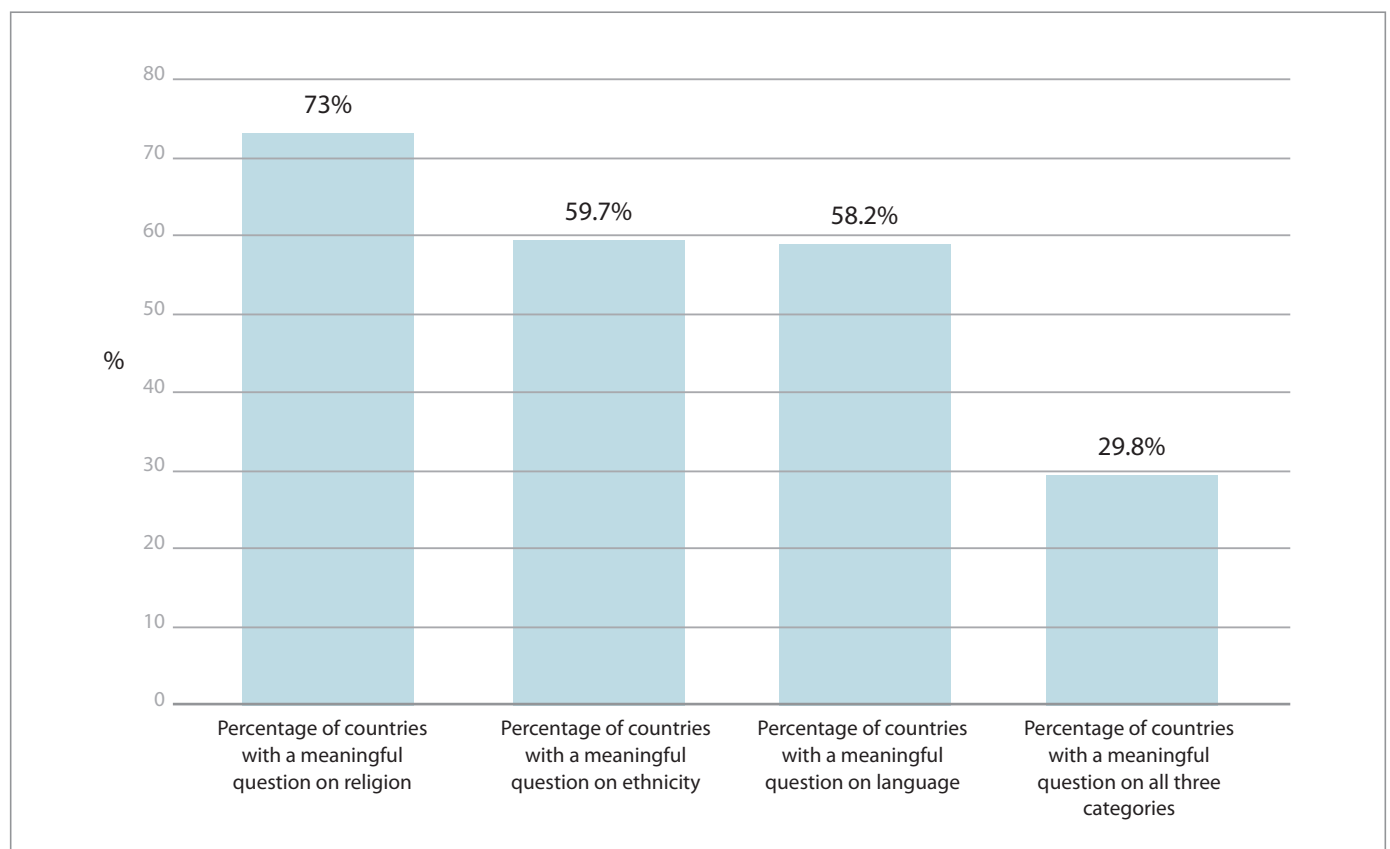
'Leave No One Behind' was a key clarion call throughout the process of developing the SDGs. Whilst the Millennium Development Goals faced criticism concerning a failure to reach all groups (Fehling et al., 2013), the new global goals were tipped to address this criticism with their commitment to meeting all targets 'for all nations, all peoples and for all segments of society'. To achieve this mission, data should be broken down by a wide range of social groups, which after much discussion and debate was cemented in the targets 'with a

commitment to disaggregate data by age, sex, disability, race, ethnicity, origin, religion or other status' (General Assembly Resolution 68/261).

Data Availability

■ Of the 67 countries with vaccination data and a question³ on religion, ethnicity and language; 73% (49) of the countries had a meaningful question on religion, 59.7% (40) had a meaningful question on ethnicity and 58.2% (39) had a meaningful question on language. However, only 29.8% (20) countries included questions allowing for disaggregation of all the three categories: religion, ethnicity and language. (see *Figure 1*).

Figure 1: DHS and MICs surveys with meaningful questions on ethnicity, language and/or religion



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■ There were 77 questions in the DHS regarding language, religion and ethnicity, but only 53 of them allowed for substantive minority disaggregation (68%). Only in three of those situations had the disaggregated data been published (3.8%). Theoretically, anybody who registers on the relevant platform can get data that has been collected but not published. However, accessing, analysing or comprehending such unpublished material actually requires considerable research abilities. Similarly, despite the fact that MICS had 100 questions on religion, ethnicity and language, 17% of them were not meaningful in terms of minority disaggregation and only 21% were published. The disaggregated results of 177 DHS and MICS questions were only published in 14% of the total cases. (Figures 2, 3 and 4)

Figure 2: A chart comparing the proportion of DHS survey questions that published and did not publish disaggregated results

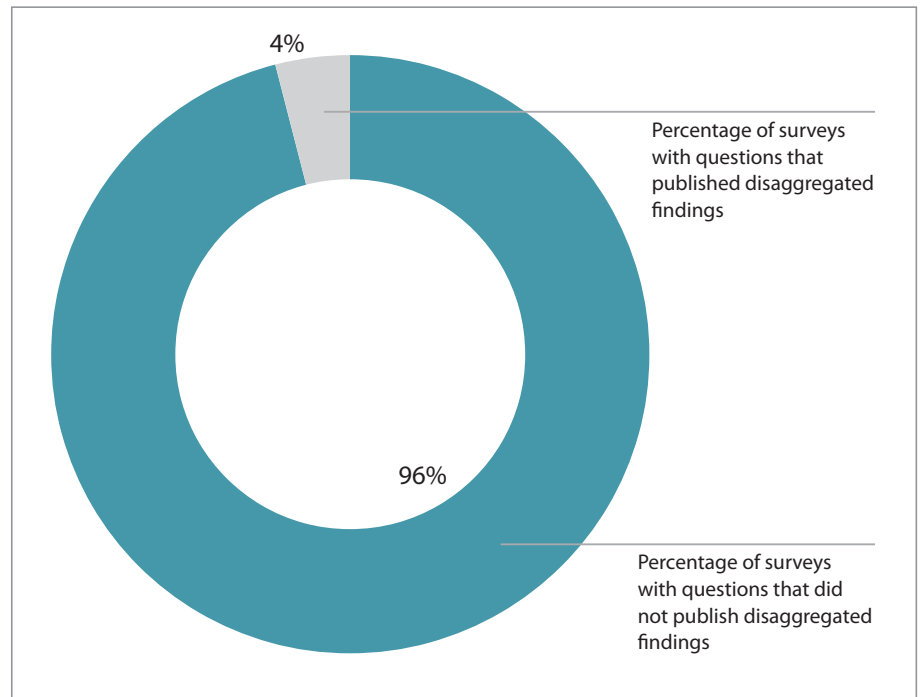


Figure 3: A chart comparing the proportion of MICS survey questions that published and did not publish disaggregated results

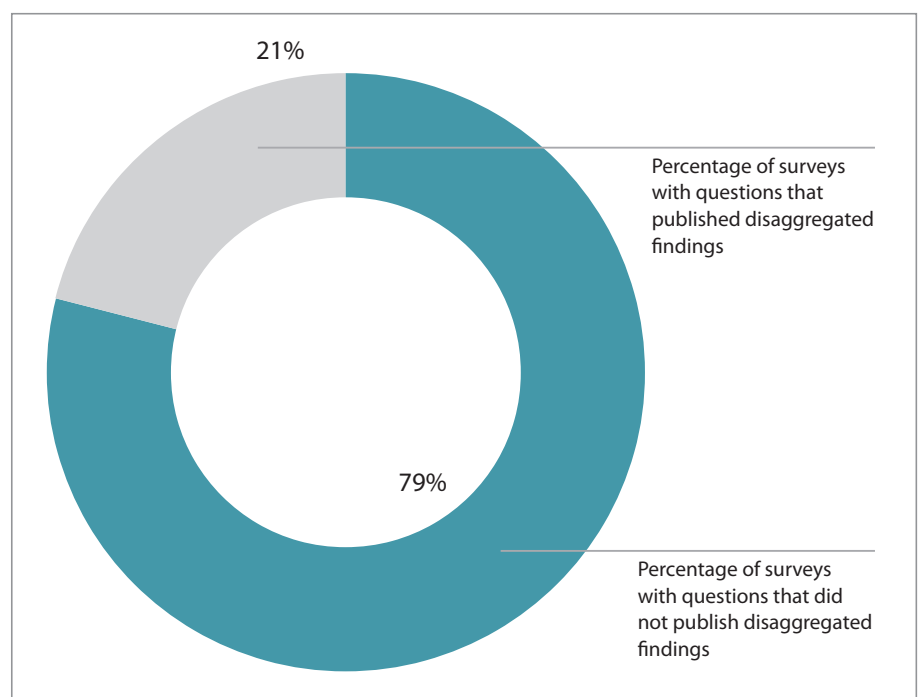
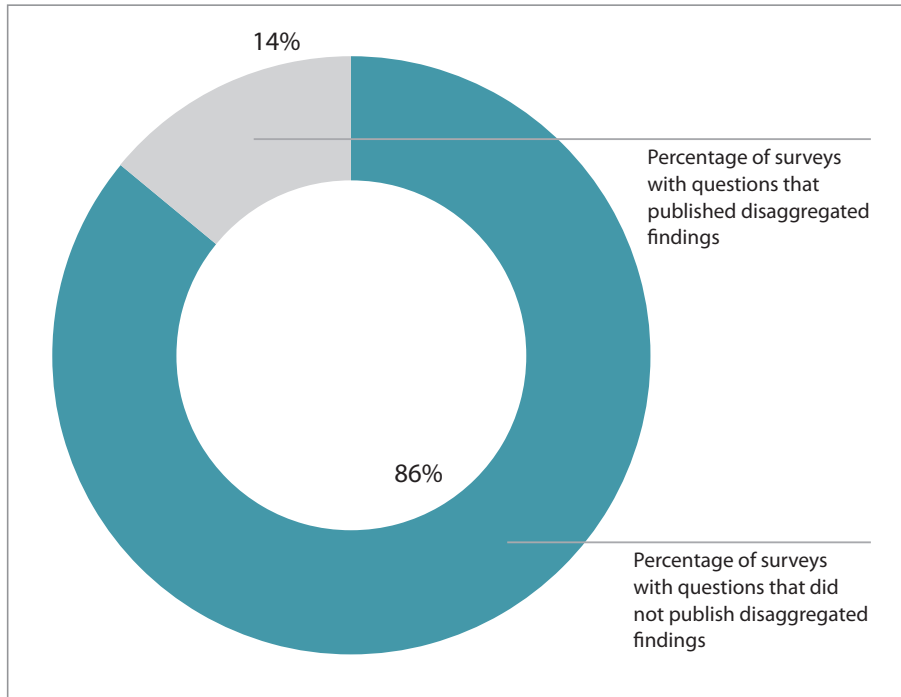


Figure 4: A chart comparing the proportion of both DHS and MICS survey questions that published and did not publish disaggregated results



■ One other way of looking at this is not survey by survey but by asking whether for each country any disaggregated data was made publicly available. Of the 35 DHS and 40 MICS countries in our sample, only 2 (6%) and 21 (52.5%) countries had respectively published disaggregated data. Overall, of the 67 distinct countries, only 23 (34.3%) had published results disaggregated by either religion, ethnicity and/or language. (Figures 5, 6 and 7)

■ Three of the published surveys currently in the public domain lacked information for each category that was referred to in the questions. Thailand, for instance, gathered data for 13 different language groupings, but the results were only released as Thai and Non-Thai. Ethnicity was similarly presented for Serbia as Serbian and non-Serbian, while for North Macedonia, it was simply broken down into Macedonian, Albanian and other groups.

Figure 5: A chart comparing the proportion of DHS countries that published and did not publish disaggregated results

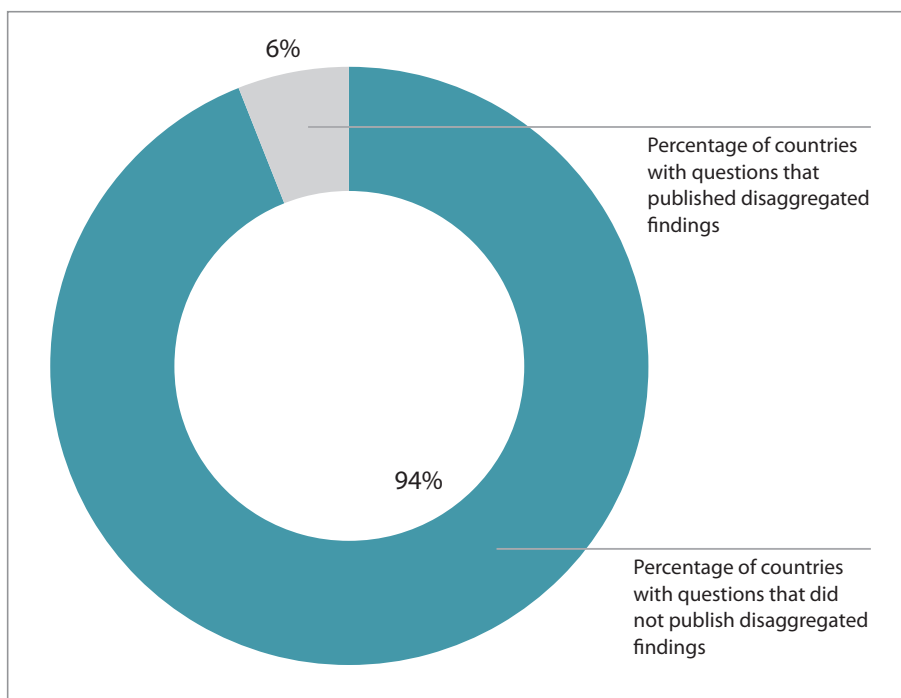


Figure 6: A chart comparing the proportion of MICS countries that published and did not publish disaggregated results

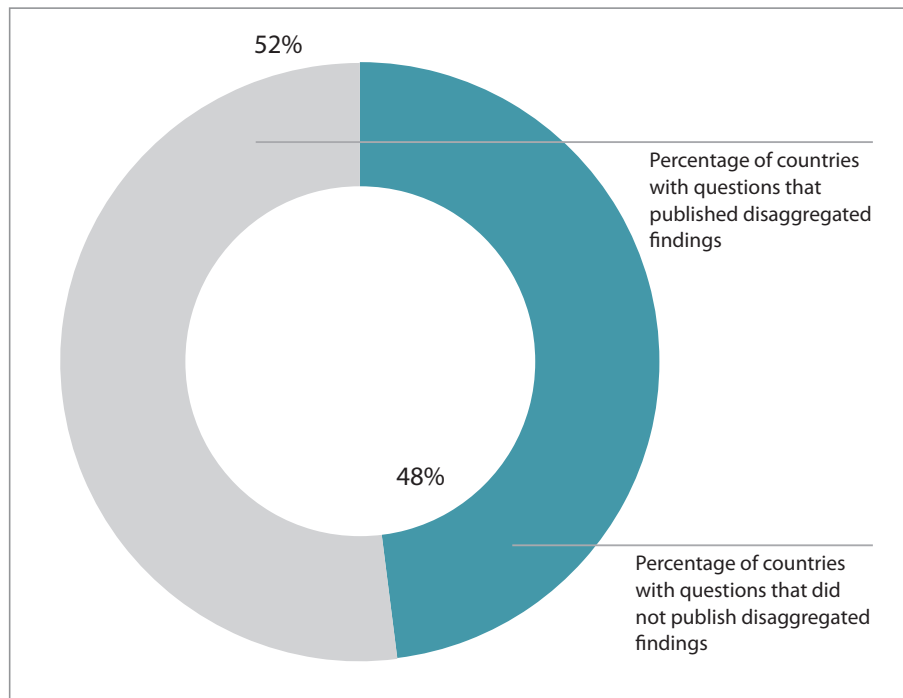
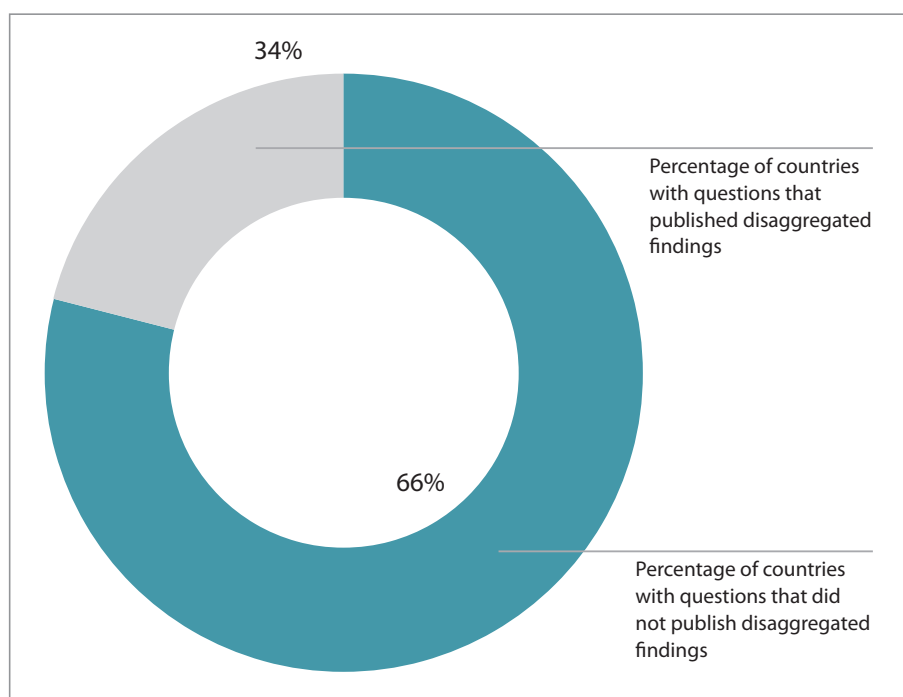


Figure 7: A chart comparing the proportion of DHS and MICS countries that published and did not publish disaggregated results



Information Gathering

- Of the three categories, linguistic minorities are least likely to have a meaningful question, a sufficient sample size and results that have been published.

Despite the fact that 72 surveys included language-related questions, only 39 of them (54.7%) included a question that was inclusive of minorities and useful for disaggregation. Due to small sample population sizes, 8 language surveys were removed (of the 13 overall), and 7 of these 8 concerned minority linguistic communities. Furthermore, we had to remove 5 surveys that had a relevant question on language, but the data was either missing or insufficient to allow for disaggregation. As a result, only 26 out of 72 surveys (36.1%) met the requirements for analysis. The odds of having results published that were broken down by language were half of having data broken down by religion and one sixth of the odds of having data broken down by ethnicity.

Results

Range of differences found when considering data

Differences by categories

- The largest difference between minority and majority groups was observed in linguistic and religious categories. Angola had the highest difference (25.7%) within language, with minorities (14.6%) being 2.7 times less likely to have received complete basic vaccination than majorities (40.3%) in the same population. Amongst countries analysed for religion,

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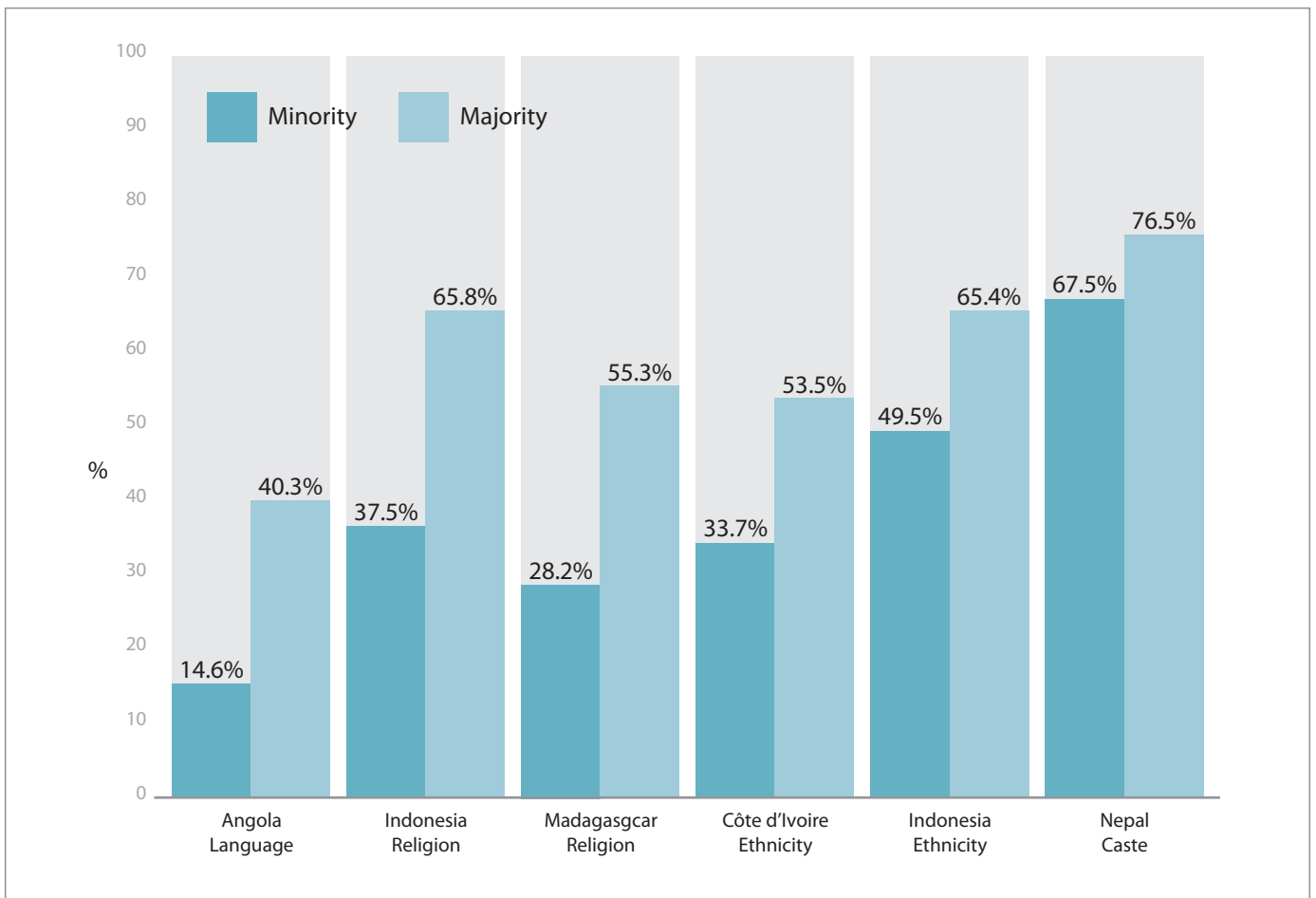
Indonesia and Madagascar have the highest difference of 28.3% and 27.1% respectively. The highest disparity is found within Madagascar where majorities (55.3%) have vaccination rates 1.9 times higher when compared to minorities (28.2%). Similarly, in Indonesia, majorities (65.8%) have a

vaccination rate 1.75 times higher than minorities (37.5%). (Figure 8)

- Amongst countries analyzed for ethnicity, Côte d'Ivoire and Indonesia had the highest difference. Minorities in Côte d'Ivoire (33.7%) and Indonesia (49.5%) had 1.5- and 1.3-times lower

vaccination rates, respectively, than majorities with mean percentages of 53.5% and 65.4%. In Nepal, there was a significant difference in caste, with minorities (67.5%) being 1.13 times less likely to have received complete basic vaccination than majorities (76.5%). (Figure 8)

Figure 8: Selected examples illustrating significant differences between mean immunization rates for minority and majority populations for each of the four minority categories



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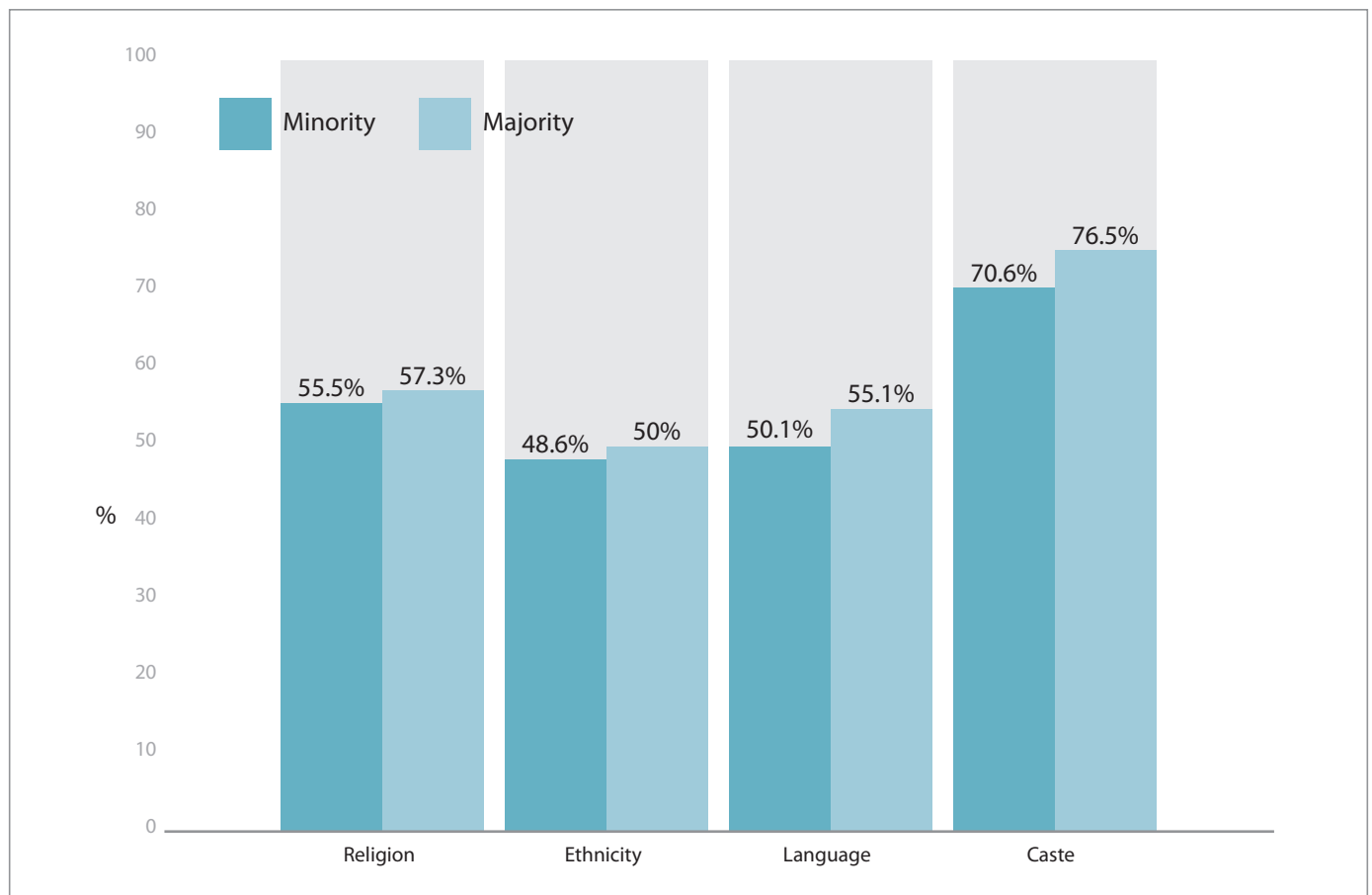
Case for geographical proxy

Where countries lacked a meaningful question on religion, ethnicity or language, the authors of this brief considered using a geographical proxy in which distinct geographical areas dominated by minorities were considered. Indonesia was one of the countries with a suitable geographical proxy (for religion and ethnicity) occupied

by the people of Aceh and Papua. According to the analyses, Indonesia has the greatest disparity in religion and ethnicity. These differences would be hidden if no geographical proxy was used. Therefore, the authors of this brief urge decision-makers and academics to take the geographical proxy into consideration as a viable alternative where data by group is not available.

Religious and ethnic minorities had marginally lower immunisation rates of 1.8% and 1.4%, respectively, as compared to the mainstream population. Rates were, however, 5% lower for linguistic minorities and 5.9% lower for caste minorities.

Figure 9: Comparison of complete vaccination rates of minority and majority groups by Religion, Ethnicity, Language and Caste



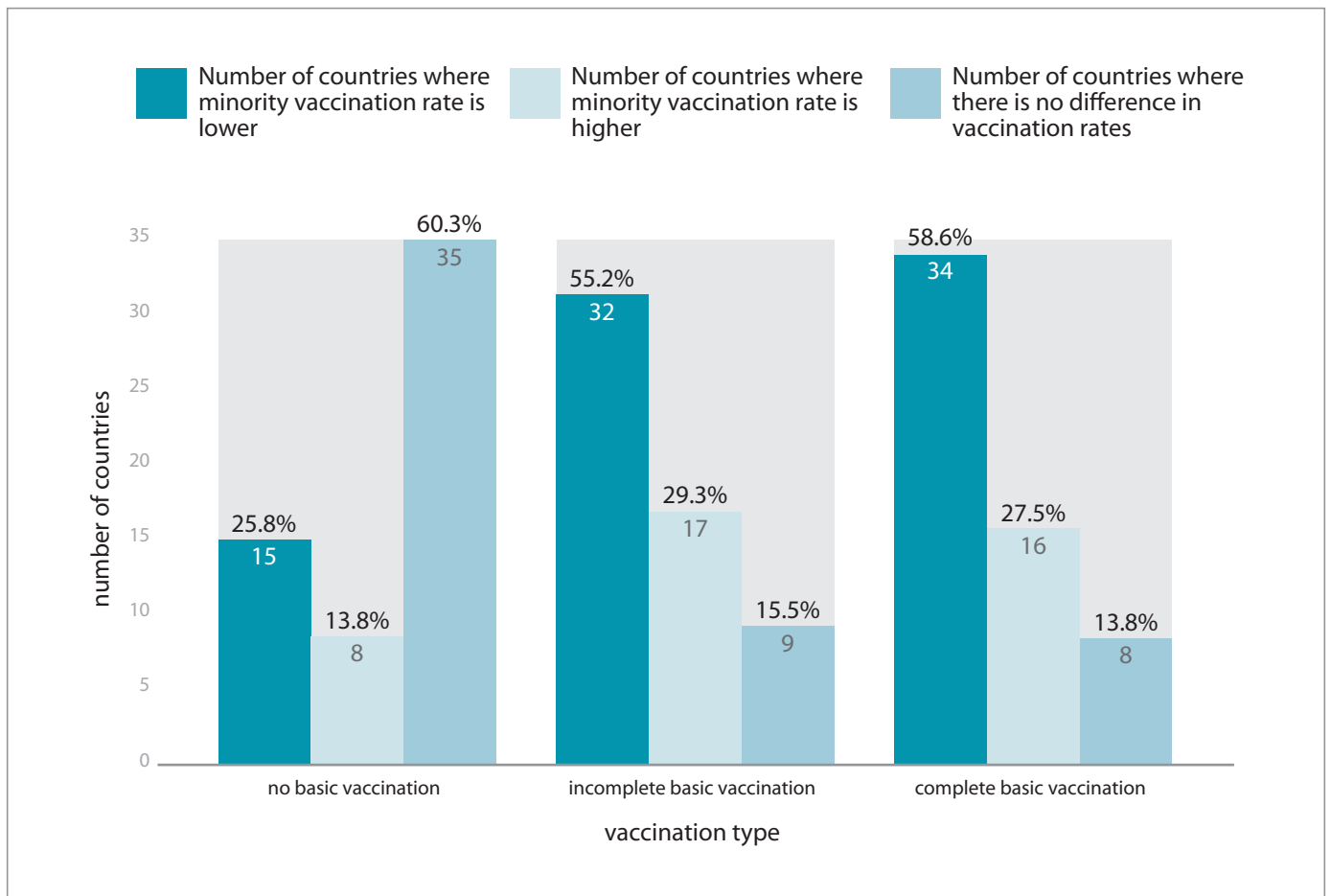
Differences between countries

■ There are more countries in all three categories—no basic vaccination, incomplete basic vaccination and complete basic vaccination—where minority vaccination rates are lower than

those of the majority population. While there are differences in all the categories, the number of Complete Basic Vaccinations shows the biggest disparity. In 58.6% of countries (34 of the 58⁴ countries), minorities had lower rates of

complete vaccination than the same country's majority population. There were only six countries (Burundi, Cuba, Guyana, Honduras, Lesotho and Rwanda) with no difference in immunisation rates across all the three categories.

Figure 10: Numbers of countries with higher and lower minority vaccination rates



■ It is not surprising that higher disparities are apparent for complete basic vaccination. Repeated follow-up visits are necessary for full immunisation. Studies have found a link between inequities in child health outcomes and vaccination status (Debie et al., 2020). Lower complete immunisation rates were linked with barriers such as time, expense and education, physical

accessibility to the health centre and availability of services (Bugvi et al., 2014, Abadura et al., 2015; Antai, 2012). Minority communities may often be disadvantaged as a result of these barriers with a single one-off universal effort reaching them; whereas they struggle to consistently access services repeatedly over a longer time period.

Even in countries where minorities overall had higher vaccination rates, this does not indicate equity in access to vaccination

Despite having a higher average than majorities as a whole, there were disparities even when subgroups were arranged within a more inclusive minority category. In some instances, significant

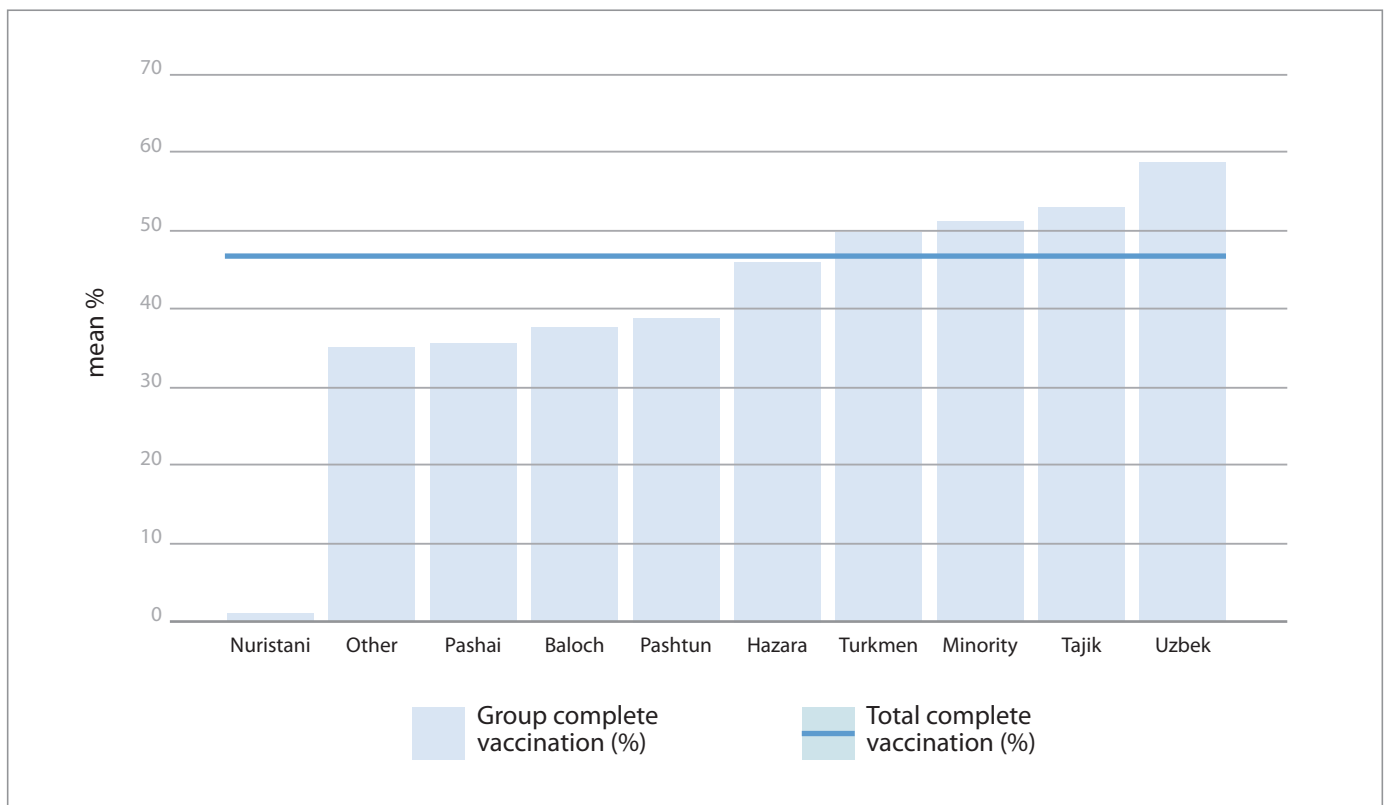
differences of some minorities were masked when averages at the national level were taken into account. As a result, we recommend that policymakers, governing bodies and academics evaluate data by community rather than relying on averages.

■ Ethnicity

When compared to the national average of 46.3%, the Nuristani

community's mean percentage of children who have had all required vaccinations is 66 times lower (0.7%). In Guinea, the immunisation rate for Toma people is 1.6 times lower (16.7%) than the country's average of 26.7%, (Figure 11). The immunisation rate for Cuba's Afro-descendant⁶ minority is 28.5%, which is lower than the country's average (39.1%).

Figure 11: All basic vaccination received by ethnic group in Afghanistan (and national average)



■ Religion

In the Central African Republic, Ethiopia, Nigeria and Zimbabwe, vaccination rates are lower among adherents of traditional or animist religions. In Ethiopia, Nigeria and Zimbabwe, traditional believers' immunisation rates are 28.4%, 12.4%

and 6.1% lower than the national averages of 43.7%, 27.9% and 79%, respectively. Furthermore, animists in the Central African Republic are three times less likely (4%) to have received every recommended vaccination than the national average (12%).

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Figure 12: All basic vaccinations received by religion in Ethiopia (and national average)

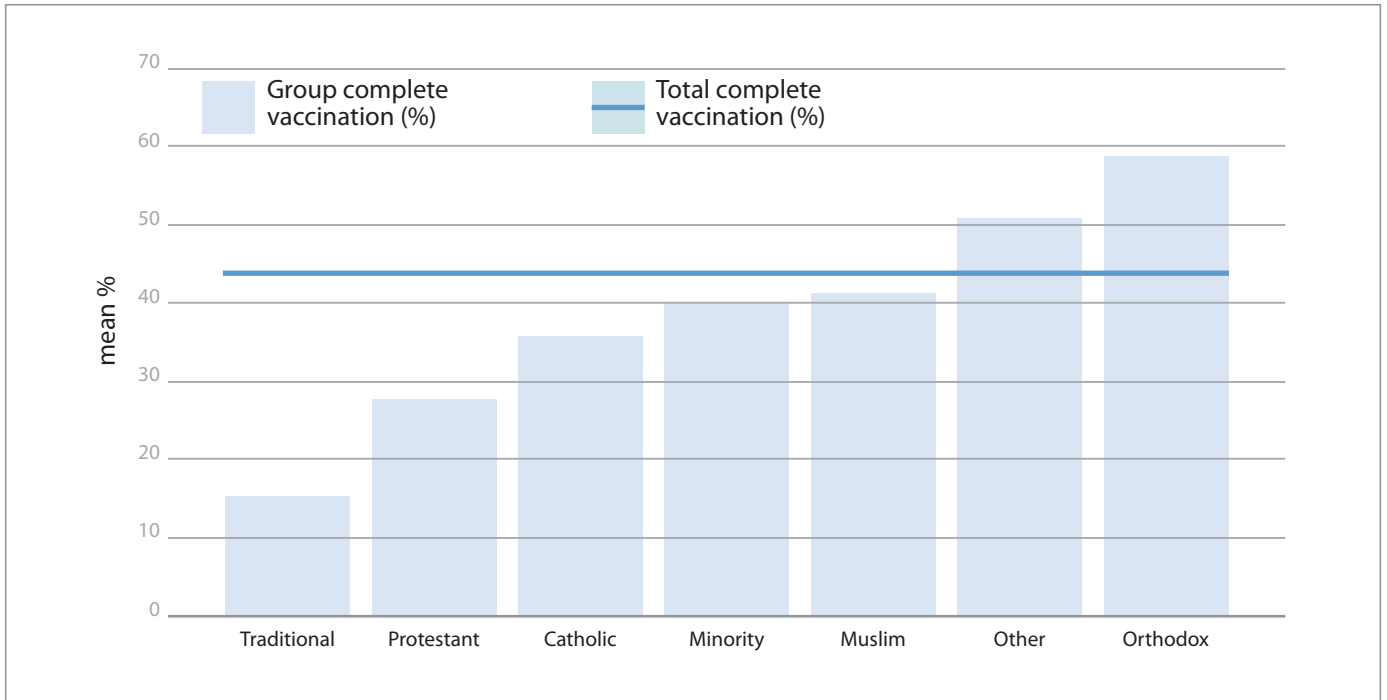
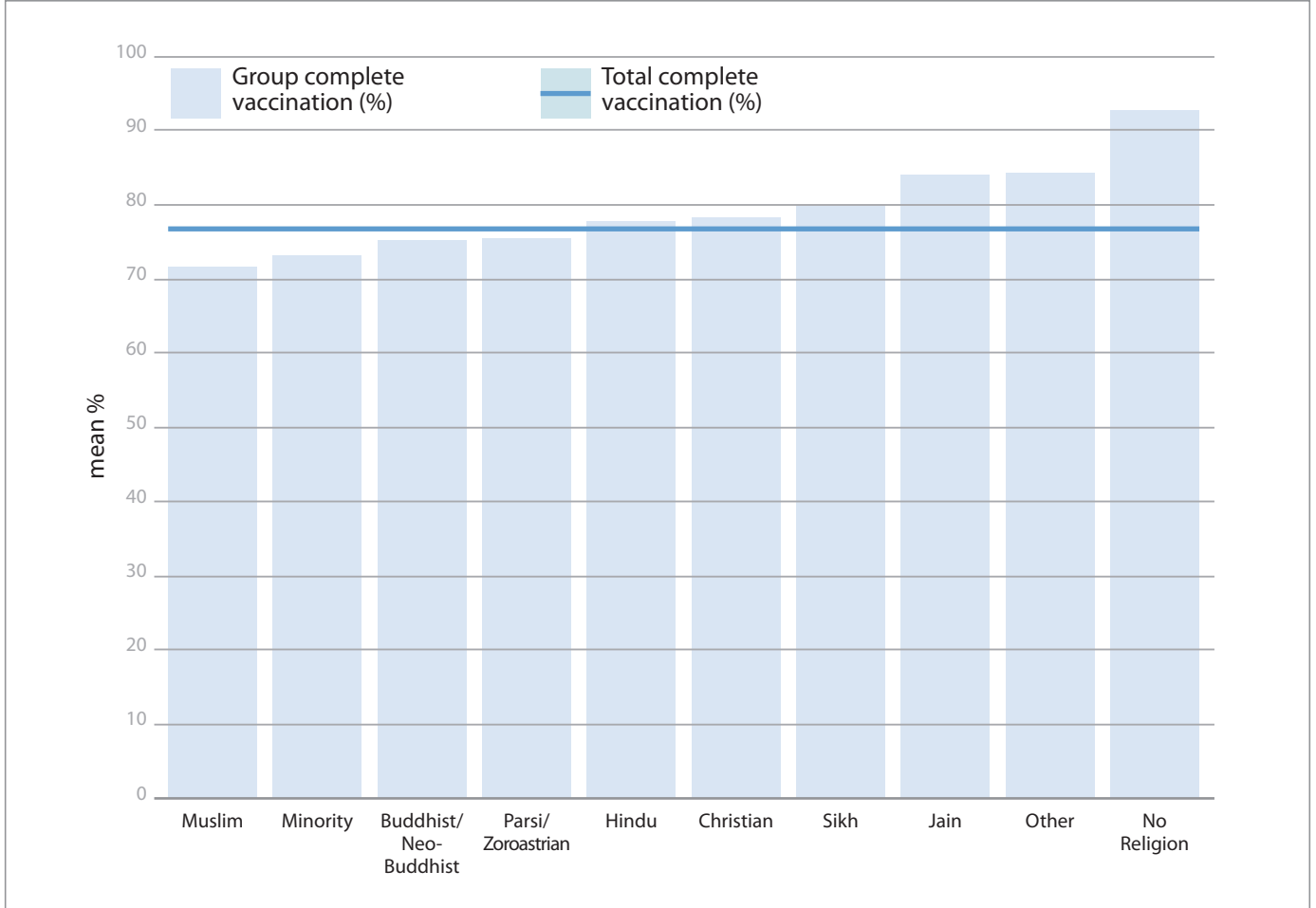


Figure 13: All basic vaccinations received by religion in India (and national average)



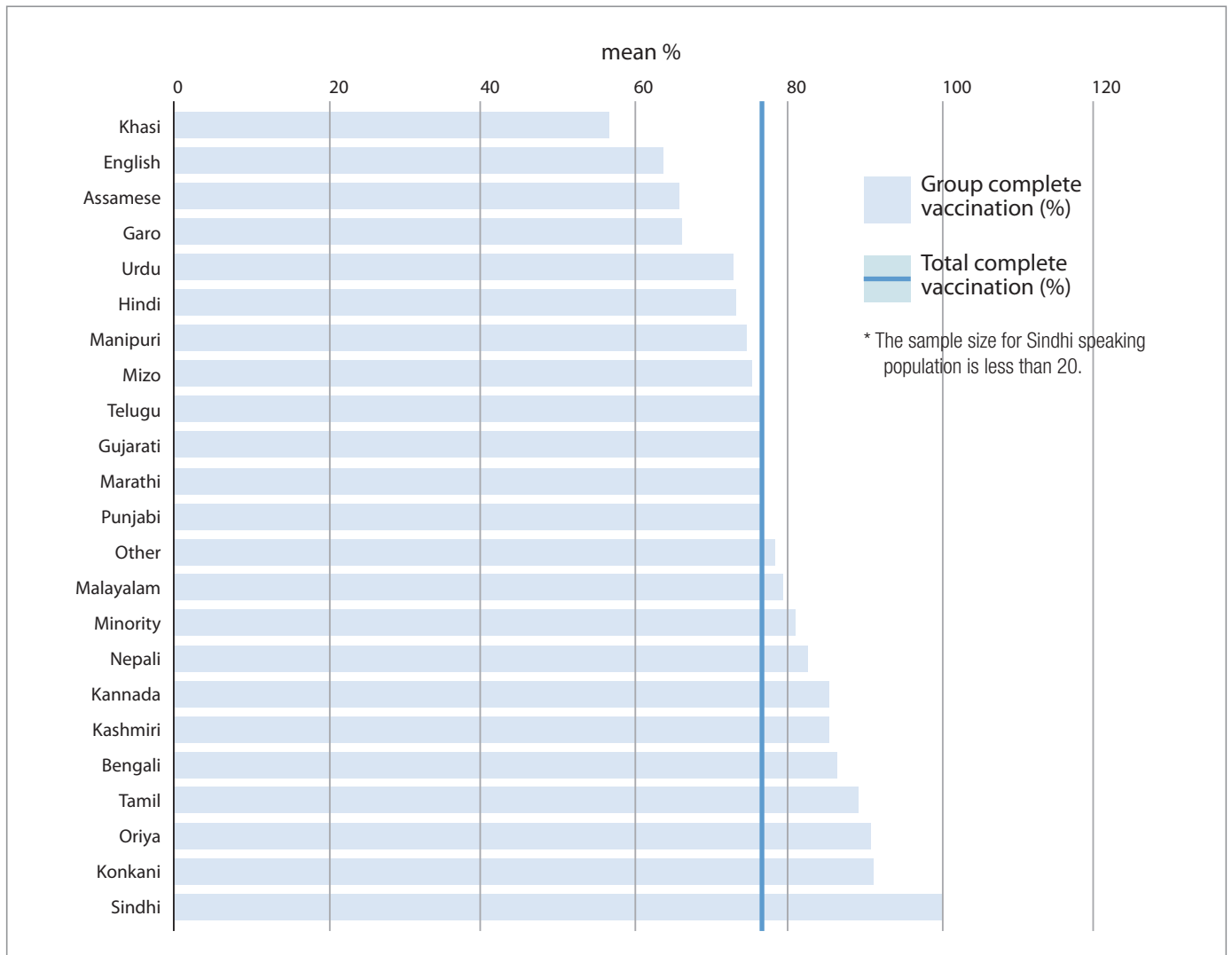
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■ In Liberia and the Turks and Caicos Islands, immunisation rates are lower among atheists or people with no religion. In Liberia, there is an 8% difference between the percentage of the minority population that has received complete vaccination (48.5%) and the national average of 56.5% and in Turks and Caicos Islands, the basic vaccination rate for nonreligious people (24.9%) is 2.8 times lower than the national population (71.7%).

■ Muslims in India and followers of religions other than Islam and Christianity (such as Bahá'ís, Hindus or Jews) in Zambia have lower immunisation rates than the respective national averages. Muslims in India had lower immunisation rates (71.7%) than the whole population (76.9%), a difference of 5.2% (Figure 13). In Zambia, the vaccination rate for people of Other Religions (those who are neither Muslims or Christians) is 65.1%, almost 10% lower than the country's average of 75%.

■ **Language**
In India, vaccination rates for the Khasi (56.8%), Assamese (66.1%) and Garo (66.2%) language groups are respectively 20%, 10.8% and 10.7% lower than the 76.9% national average. In Iraq, the Turkmen group has a vaccination rate that is 3.2% lower (11%) than the country's average (14.2%). Furthermore, vaccination rates are 8.3 times lower (1.7% vs. 14.2%) among linguistic populations who speak languages other than Arabic, Kurdish, Turkmen and Assyrian such as Syriac and Armenian.

Figure 14: All basic vaccinations received by language in India (and national average)



Discussion and Recommendations

The 'Big Picture' may not necessarily represent the entire situation

Complete, disaggregated and inclusive statistics may be utilised to advocate for people who have been left behind. Aggregated data for the total population can mask differences across groups of the population so it is not possible to determine who is being left behind. Even using a more inclusive minority category, aggregated data masks inequalities across population groups. Data must be more fully disaggregated in order to assess and analyse confounding factors and the intersectionality of inequality.

Household surveys as indicators

Household surveys dominate research and are often recognised as the most reliable source of data in global south countries. They fill a need by providing more reliable demographic and socioeconomic data. Household surveys offer untapped potential. We highly recommend combining minority status, age, wealth index and location of residence to produce indicators for immunisation rates across several dimensions to give the data greater strength and utility. Currently, there is insufficient disaggregation of outcome data by population characteristics for use by governments at the local level. For instance, one expert development group reports that 'The communications and policy departments in UNICEF country offices, for example, make great use of MICS data, but their teams working in the

field – in health, education, nutrition and social protection – find it insufficiently granular to be of much use.' (Development Initiatives, 2021, p. 7) .

While a key source of data, surveys have limitations for monitoring or research activities. DHS and MICS population surveys take a long time and are normally done at intervals of five years or more. As a result, there will be no data to monitor key health trends between survey cycles. Many household surveys also collect data solely from individual houses, leaving out key institutions. As a result, information on the immunisation rate of children in care homes and refugee households may be absent. In addition, the surveys struggle to capture data from nomadic populations, asylum seekers and those who are stateless or in situations of irregular migration.

Another difficulty in monitoring sustainable development objectives is that monitoring national statistics are prioritised over local data that is more valuable to people in charge of fulfilling the targets. Therefore, statisticians are under pressure to acknowledge that calculating rates is more crucial than focusing on data about service availability (Development Initiatives, 2021). We tried to compare service provision in a region that was mostly populated by minorities (geographical proxy) with that of the national average as part of our study, but we were unable to locate even 10 countries with complete, accurate and similar statistics. Similarly, just one of the 67 countries with vaccination data and questions on religion, ethnicity or language raised concerns about why its citizens were not immunised in their survey design.

Data Sources

Household surveys are a major source of data to explore and analyse SDGs, as the International Organization for Migration has done (Jeffers, K., 2018). As is the case for all data sources, it has limitations. Other data sources should be explored and developed to provide the needed information. National Statistical Offices can look into administrative data sources, censuses, or non-official sources of data like other official statistical producers (like the UN agencies), charities, or academics that abide by formal guidelines and principles and are transparent, allowing for consideration of these sources to meet the NSOs standards. These data sources will have their own limitations that need to be evaluated. We recognise that the lack of an agreed-upon worldwide definition for minority, ethnicity, religion, race, or cultural markers limits the usefulness of some data sources. This can be addressed, however, by specialised awareness raising within the National Statistical Offices and other data providers for individually tailored techniques to collect data from people in human rights compliant ways and share it with policymakers and the government.

Financial investment in data and statistics from national and international sources should be continued and increased to ensure that high quality, disaggregated and appropriate scale data is available. According to the WHO's SCORE report, most low-income countries rely largely on external funding for surveys, with only 3% of low-income country surveys and 8% of lower-middle-income country surveys wholly sponsored by the government (WHO, 2020). Similarly, NSOs must be more independent and politically neutral, increase their capacity and competence, and adopt a culture of constructive collaboration.



Ethnicity as consideration for disaggregation related to vaccines for all (Target 3.8)

SDG 17.18 highlights the need to support developing countries to increase the availability of 'high quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity and migratory status'. Some SDG targets do include references to race, ethnicity and religion (e.g. 10.2: 'By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status'), but the linked indicator often has dropped these potential discrimination factors (e.g. 10.2.1 'Proportion of people living below 50 per cent of median income, by sex, age and persons with disabilities'). Some targets and indicators include reference to indigenous peoples (e.g. 4.5 and 4.5.1 and 2.3.2) but no reference is made to other facets of ethnicity.

But while there were intentions to eventually make the ethnicity data accessible for some indicators, this was not the case for objective 3.8,⁷ which aims to provide immunisations for everyone. Numerous studies have looked at and discovered a link between ethnic, religious and/or cultural views and immunisation uptake (Forster et al., 2017; Pierik, 2017), especially in the last two years. Data on vaccination rates, attitudes toward vaccination and reasons for hesitancy must therefore be gathered, examined and published for each of the three groups.

The Inter-Agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs) was asked to establish a working group on data disaggregation by the UN Statistical Commission (UNSC) during its 47th session in order to improve national capacities and provide the required statistical standards and tools. For Target 3.8 of the SDGs that includes vaccines for all, the IAEG-SDGs accepted the most disadvantaged population as the group of minimum required disaggregation dimensions, however the relationship and significance of ethnicity, language and religion were not recognised. (*Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans*, 2019). It is reported that geographic location and income will be included as disaggregation dimensions in the future. However, we recommend that taking into account disaggregation based on language, ethnicity and religion must start now. Delaying this any longer cannot be justified (Tadros & Thomas, 2021).

Recommendations for surveys

In light of the fact that some disadvantaged groups are not represented in the statistics, we suggest that surveys should additionally focus on populations that are left out and undercounted. We also recommend that governments, policymakers and others who share the surveys use the power of data. Consider, for instance, how education levels, racial or ethnic minorities and wealth quintiles relate to vaccination rates. It is necessary to provide tools that make data easier to interpret and analyse while informing policy options to counter the current downward trend in vaccination rates.

Sample Sizes

We had to exclude 13 entries due to low sample size even when groups were aggregated into a 'minority category'. Small sample sizes make findings less reliable. Surveys need to increase sample sizes to allow for better data collection, generation, analysis and sharing for disadvantaged populations. Where minority populations have small numbers, the scale of a nationwide survey that would generate reliable findings about this may be very costly. For this reason, MICS has established a positive survey model that focuses on a specific potentially disadvantaged population (e.g. Roma in a number of Eastern European countries as well as Maasai in Kenya).

Goal 3.8 of the SDGs states that the countries aim to 'achieve universal health coverage, including financial risk protection, access to quality essential health care services and access to safe, effective, quality and affordable essential medicines and vaccines to all'. The goal of Strategic Priority One of the 2030 Immunisation Agenda is to ensure that 'effective, efficient and resilient immunisation services are accessible to all people as an essential part of primary health care and thereby contribute to universal health coverage' (WHO, 2021, p. 32). To accomplish and monitor these goals, data needs to be disaggregated to show how different groups are progressing. Data needs to capture the rate and the extent of inclusion of different population groups. Since the 2030 Immunisation Agenda focuses on 'vaccines for all' the SDGs cannot be achieved or monitored without inclusive data.

Policies and data

Data gaps and a lack of demand are also caused by a lack of policies. Countries must explore if data gaps for certain demographic groups are the result of a lack of interest, inactivity or intentional exclusion due to information suppression. Decision-makers will be able to modify policies as necessary with the help of these insights. Policymakers must make sure that there is a demand for more and better-quality data at every level of analysis and policy making, which leads to improved and more effective data.

The Health Equity Examination Toolkit (HEAT) is a reanalysis of DHS, MICS and reproductive Health Surveys from more than 100 countries that the WHO produced to assist assessment of inequities within countries using data (*Health Inequality Monitor*, 2022). Users of the interactive data visualization tool may examine disparities in statistics that are broken down by education level, location of residence, economic position, age and sex, but not by race, religion, language, or other marginalisation factors (including importantly disability) (*RMNCH Interactive Visualizations*, 2022).

Data Equity

Researchers, policymakers and governments should examine data for both quality and quantity while identifying, where possible, existing constraints. A Countdown 2030 (CD2030) examination of the inclusion of equity data within countries and the use of data for

accountability in reproductive, maternal, newborn child and adolescent health (RMNCAH) for ten Sub-Saharan African countries discovered major gaps in efforts to eliminate inequities. The study ranked policies based on core concepts, coverage of specific groups and a human rights-based approach to health. For example, the Malawi Health Sector Strategic Plan II, which stresses equal access to health care through a health package that outlines interventions for women and children, had 93% coverage but just 20% quality. Additionally, just 35% of institutions either knew about the package services or were implementing them. ('Regional Workshop on Reducing Inequalities in Reproductive, Maternal, Newborn and Child Health in Sub-Saharan Africa', 2019).

Furthermore, several countries sought to disaggregate indicators but had insufficient systematic monitoring and evaluation of data. Similarly, there is no information in official records or digital platforms to track whether or not people were left behind or even excluded. Inadequate data access, poor communication and a lack of comprehension of current data were all barriers to data fairness. The most overlooked gaps occurred between economic groups and differences caused by diversity (both religious and cultural), corruption, financing, unfair resource allocation and poor governance. ('Regional Workshop on Reducing Inequalities in Reproductive, Maternal, Newborn and Child Health in Sub-Saharan Africa', 2019).

Data Charter and Data Governance

According to the five principles⁸ of the Inclusive Data Collection Charter, all populations must be considered in the dataset and all data must be

disaggregated and retrieved from all sources. These include both official sources such as data from national statistical organizations and non-official sources such as citizen generated data (Ballerini & Bergh, 2021) which is produced by organisations to monitor the issues affecting them. Capabilities for collecting, analysing and using disaggregated data must also be developed. The Inclusive Data Collection Charter also promotes accountability, privacy and confidentiality in order to prevent the exploitation of personal data. (Global Partnership for Sustainable Development Data, 2015). We urge all regional, national and internationally comparable surveys to consider these principles.

Throughout the entire data analysis process, including collection, storing, analysing and sharing of data, we urge survey makers, survey takers and survey publishers to use the Human Rights-Based Approach to Data (UN OHCHR, 2018). This resource emphasises the need for all groups to be included in all parts of the data gathering process and for vulnerable or marginalised groups to be properly represented. In situations when it may be impossible to interact with groups owing to their legal status, marginalisation or unfavourable preconceptions, National Human Rights Institutions and other competent representative stakeholders must join to give perspectives. Asif and Kienzler investigated the complexity and experiences of refugees, asylum seekers and undocumented migrants seeking health care in the United Kingdom, emphasizing the need to combat illness, address socioeconomic determinants of health and offer meaningful health and social care support (Asif & Kienzler, 2022). Deal et al. also investigated the hesitations and numerous obstacles to health care access, as well as vaccination hesitancy, among undocumented migrants, asylum

seekers and refugees (Deal et al., 2021). Data collection, disaggregation, analysis and sharing must always be transparent. Privacy and secrecy must be preserved and no identifiable information should be made public, unless prior permission from the individual has been obtained. National

Statistical Officers must hold themselves accountable in order to guarantee that any given data protects and fulfils human rights (UN OHCHR, 2018).

Tables and Charts

Table 1: DHS characteristics by survey questions on Religion, Ethnicity and Language

DHS	Survey with a question	Meaningful for Minority Disaggregation	Published
Religion	26	26	1
Ethnicity	17	15	2
Language	34	12	0
Total	77	53	3

Table 2: MICS characteristics by survey questions on Religion, Ethnicity and Language

MICS	Survey with a question	Meaningful for Minority Disaggregation	Published
Religion	31	31	3
Ethnicity	31	25	16
Language	38	27	2
Total	100	83	21



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Notes

- 1 With grateful thanks to Luciana Viegas of *Vidas Negras com Deficiência Importam*, Brazil, who introduced the authors to this phrase.
- 2 The co-author prefers to remain anonymous for security reasons.
- 3 For an explanation of methodology and key terms used please see www.minorityrights.org/nodataisdatamethodology.
- 4 The selection of countries for data analysis was based on four criteria: (i) those with a question about religion, ethnicity and/or language; (ii) those with meaningful questions; (iii) datasets with enough data to allow for disaggregation; and (iv) those with a large enough sample size when groups are divided into 'majority' and 'minority' groups. Only 58 of the 67 countries with vaccination data and a question about religion, ethnicity and/or language met the other requirements and were taken into consideration for analysis.
- 5 Of the 35 countries that had no difference in basic vaccination between the two groups; there were nine countries where there was no difference between populations that had gotten at least one dose of the basic immunization, since the percentage of persons who had not received these vaccines was zero.
- 6 The term 'Negro' is the one used in the MICS survey question and published dataset, although it is not a term in common or recommended use globally.
- 7 The SDG's objective 3.8 strives to 'Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all'.
- 8 The five principles of data are as follows : i) All Populations must be included in the data; ii) All data should wherever possible be disaggregated in order to accurately describe all populations; iii) Data should be drawn from all available sources; iv) Those responsible for the collection of data and production of statistics must be accountable; v) Human and technical capacity to collect, analyse and use disaggregated data must be improved, including through adequate and sustainable financing (Global Partnership for Sustainable Development Data, 2015).



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Minority Rights Group International

Minority Rights Group International (MRG) is a non-governmental organization (NGO) working to secure the rights of ethnic, religious and linguistic minorities and indigenous peoples worldwide, and to promote cooperation and understanding between communities. Our activities are focused on international advocacy, training, publishing and outreach. We are guided by the needs expressed by our worldwide partner network of organizations, which represent minority and indigenous peoples.

MRG works with over 150 organizations in nearly 50 countries. Our governing Council, which meets twice a year, has members from 10 different countries. MRG has consultative status with the United Nations Economic and Social Council (ECOSOC), and observer status with the African Commission on Human and Peoples' Rights (ACHPR). MRG is registered as a charity and a company limited by guarantee under English law: registered charity no. 282305, limited company no. 1544957.

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Given the importance of data when seeking to better understand health programmes and key aspects of global health such as vaccination, this report cogently argues that current datasets concerning immunisation need to take into serious consideration an inclusion focused and human rights-based approach.

The research that underpins this collaborative report written by Minority Rights Group (as part of the CREID project), clearly shows that current data on immunisation programmes lacks precise and representative data on minority groups. This comes with the risk that groups may still be being left behind, with the ability to track or respond to this severely limited.

At the mid-point of the Sustainable Development Goals period, with just seven years left until 2030 and in order to deliver on the central commitment of the Leave No One Behind campaign, this report argues that clear data about which groups are at risk of neglect is currently absent. The brief assesses the available data regarding childhood routine vaccinations and ethnicity, language and religion and offers suggestions on the relation between childhood vaccinations and diversity across several countries.

No Data is Data has identified gaps in the uptake of life-saving vaccines for children as well as data collected, analyzed or published in the most recent international health surveys and reports covering 71 countries. The analysis shows that 48 years since the inception of WHO's Expanded Programme on Immunisation (EPI), it is still difficult to quantify or understand the uptake of vaccination of minority communities.

In an effort to advance data equity, this report argues that the entire data analysis process, including the collection, storing, analysing and sharing of data should take good care that vulnerable or marginalized groups are properly represented. Furthermore, the authors argue that all regional, national and internationally comparable surveys should operate according to the five principles of the Inclusive Data Collection Charter, in the context of which all populations must be considered in the dataset and all data must be disaggregated and retrieved fairly and in a representative manner.

The brief is supported with graphs and visuals that provide a concise and easy-to-grasp account of current limitations in the immunisation datasets, particularly in terms of a lack of representation of ethnic, linguistic and religious inclusivity and diversity within current vaccination monitoring and data collection programmes at the international level.

