# Policy on use and sharing of data collected in Member States by the World Health Organization (WHO) outside the context of public health emergencies<sup>1</sup> (Provisional)

#### 22 August 2017

The primary purpose of data sharing is to advance public health by permitting analyses that allow for the fullest possible understanding of health challenges, to help develop new solutions, and to ensure that decisions are based on the best available evidence. The purpose of this document is to clarify current policy and practice on use and sharing of data collected in Member States by WHO outside the context of public health emergencies.

The policy is organized in the following sections:

**Background**: pages 1-5; **Policy Elements**: pages 5-8;

Annexes: Pages 9-16.

Annexes include:

Annex 1. Examples of Open Data Policies of National Governments (page 9)

Annex 2. Terms and Conditions for Data-Use of Selected Agencies (page 13)

Annex 3. Data Provided to WHO (page 14)

**Annex 4.** Text for inclusion in Data Collection Forms (page 16)

#### Data sharing policies of other organizations

The benefits of sharing data have been recognised by governments and intergovernmental organizations around the world. For example, the Open Government Data initiative of OECD "is a philosophy – and increasingly a set of policies – that promotes transparency, accountability and value creation by making government data available to all." Examples of the open data policies of national governments (from 24 countries, mainly OECD) are in Annex 1.

The large United Nations Commodity Trade Statistics Database (COMTRADE) contains over a billion trade records (comtrade.un.org). UN data is the "clearing house" for multiple databases that have been made available by many different UN agencies, including WHO.

<sup>&</sup>lt;sup>1</sup> Policy statement *Developing Global Norms for Sharing Data and Results During Public Health Emergencies* (as of 13 April 2016), <a href="http://www.who.int/wer/2016/wer9118/en/">http://www.who.int/wer/2016/wer9118/en/</a> or www.who.int/ihr/procedures/SPG data sharing.pdf

<sup>&</sup>lt;sup>2</sup> http://www.oecd.org/gov/digital-government/open-government-data.htm

These UN databases are freely available for download from the UN data website (data.un.org).

The World Bank was one of the first global agencies to adopt an open data policy (2010) and now provides open access to data on 1400 development indicators that are freely available and may be reused (databank.worldbank.org). A summary of terms and conditions for data sharing, used by the World Bank and other agencies, is in Annex 2.

In addition, research and funding agencies are publishing more open data sharing policies and positions, including many national European and North American research agencies, the European Commission, and the Bill and Melinda Gates Foundation.

#### Data sharing as a constitutional function of WHO

The collection, analysis, publication and dissemination of data has been a core part of WHO's mandate. The constitutional functions of WHO are, among others, to "establish and maintain such administrative and technical services as may be required, including epidemiological and statistical services; to promote (...) research in the field of health; and to provide information (...) in the field of health" (Article 2 of the WHO Constitution).

More specifically with regard to statistical and epidemiological data, under Article 63 of the WHO Constitution, each Member State "shall communicate promptly to the Organization important (...) statistics pertaining to health which have been published in the State concerned." Article 64 provides that each Member State "shall provide statistical and epidemiological reports in a manner to be determined by the Health Assembly." Article 65 states that each Member State "shall transmit upon the request of the Executive Board such additional information pertaining to health as may be practicable."

With regard to the Constitution, including the provisions already mentioned, the Twentieth World Health Assembly adopted the *WHO Nomenclature Regulations 1967*, which are still in force, and are today largely known for their link with the *International Statistical Classification of Diseases and Related Health Problems* (ICD). It is important to recall, however, that one of the original purposes of the Nomenclature Regulations, still relevant today, was to commit Member States to compile and publish certain sets of data, namely statistics of causes of death (Nomenclature Regulations, Article 4) and share these with WHO (Nomenclature Regulations, Article 6).

The principal importance of data collection, analysis, publication and dissemination is recorded in many other WHO documents. The UN has formally recognized WHO as the appropriate agency for the collection, analysis, publication, standardization, dissemination and improvement of statistics within WHO's sphere (Article XIII of the relationship

agreement between WHO and the UN), most of WHO's agreements with other UN system entities and other inter-governmental organizations provide for collaboration in the area of statistical services, and many of WHO's Basic Agreements with countries provide that the governments of Member States "shall collaborate with the Organization in the furnishing and compilation of findings, data, statistics and (...) other information."

In practice, the Secretariat collects, analyses, publishes and disseminates data under and within the limits of the specific public health missions that WHO Member States continue to give to the Organization through, in particular, resolutions and decisions of the Health Assembly and the Executive Board.

However, despite increasing demand for data, and despite the decisions and resolutions of governing bodies, WHO has not previously had a systematic and comprehensive policy on data sharing outside the context of public health emergencies.

#### **Previous WHO initiatives on data sharing**

In addition to provisions within the WHO Constitution, the present data sharing policy builds on historical WHO data advances, such as the introduction of the World Health Statistics Report and the Global Health Observatory as well as a series of initiatives by WHO to improve access to health information, which include:

- May 2010: WHO set out, along with other major funders of health research, guiding principles and desired goals that would promote the more effective use of data generated from funded research.<sup>3</sup>
- July 2014: WHO launched its open access policy, which applies to all articles or chapters in non-WHO publications that are authored or co-authored by WHO staff or produced by individuals or institutions funded in whole or in part by WHO.<sup>4</sup> Following this, the *Bulletin of the World Health Organization* became fully open access,<sup>5</sup> and a comprehensive open access publication policy for all WHO publications was issued.
- September 2015: Following a consultation with research funders, nongovernmental organizations and publishers, WHO published a position statement entitled *Developing Global Norms for Sharing Data and Results during Public Health Emergencies*. <sup>6</sup> This consultation recognized that public health data belong to the countries where they are

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<sup>&</sup>lt;sup>3</sup> Sharing research data to improve public health: A joint statement by funders of health research (Washington DC, May 2010).

<sup>4</sup> who.int/about/policy/en/

<sup>&</sup>lt;sup>5</sup> The Bulletin of the World Health Organization is an open access journal published under the terms of the Creative Commons Intergovernmental Organization (IGO) License (CC BY IGO 3.0).

<sup>&</sup>lt;sup>6</sup> www.who.int/medicines/ebola-treatment/blueprint\_phe\_data-share-results/en/

- generated, but that the knowledge derived from these data constitutes a global public good.
- February 2016: Following the declaration of the current Zika virus outbreak as a Public Health Emergency of International Concern, WHO launched Zika Open.<sup>7</sup>
- April 2016: WHO published "Best practices for sharing information through data platforms: establishing the principles".
- June 2016: WHO and collaborators published "Guidelines for Accurate and Transparent Health Estimates Reporting: the GATHER statement", 9 which encourages WHO to share datasets that are used to calculate estimates of disease burden and trends.
- November 2016: WHO expanded the terms and conditions under which the organization's publications are issued so as to permit free reuse for non-commercial purposes, making WHO an open-access publisher.

### Data sharing benefits and measures to mitigate potential risks

Data sharing potentially serves to:

- empower Member States to make better decisions about public health and resource allocation (including based on health expenditure data), when given access to data from a wide range of countries
- permit WHO and other partners to help establish and curate national data bases to eliminate errors in data, and to support the correct interpretation of data, including by repeated independent validation
- advance scientific understanding by allowing for analysis and hypothesis testing by multiple groups of researchers
- maximize transparency and accountability in tracking global progress of health programmes and in the conduct and funding of scientific investigations
- provide for better-informed activities to establish global health guidelines, norms and standards
- promote more complete and reliable systematic reviews and meta-analyses
- lead to more comprehensive estimates of morbidity and mortality, more comprehensive estimates of the effect of exposures and health interventions, and improved systems and results in pharmacovigilance, including intervention coverage data
- build trust among institutions that contribute and use data

To avoid adverse consequences, the process of data sharing should:

- safeguard the security of sensitive data, which may influence e.g. travel and trade
- safeguard the privacy and anonymity of individuals

<sup>&</sup>lt;sup>7</sup> www.who.int/bulletin/online\_first/zika\_open/en/

<sup>8</sup> www.who.int/bulletin/volumes/94/4/16-172882

<sup>&</sup>lt;sup>9</sup> The Lancet, published online June 28, 2016 http://dx.doi.org/10.1016/S0140-6736(16)30388-9

- safeguard people and populations from being stigmatised or unfairly targeted
- safeguard the interests of the Member States that share the data
- promote capacity strengthening within Member States that collect and share data
- be compatible with assurances made to patients, research participants and other relevant parties about the ways in which the data (anonymised or otherwise) would be used, shared, stored or protected, and with the legitimate expectations that such individuals may have about data sharing.<sup>10</sup>

#### Elements of the policy on data sharing

Against this background, this document presents WHO's policy on data use and sharing. The policy applies to data provided to WHO by Member States (types listed in Annex 3), other than data which are published by Member States without any restrictions on their use.

This data sharing policy:

- covers the use and sharing of data only, not biological samples.
- covers the use and sharing of data collected by WHO in, and/or provided to WHO by, Member States (types listed in Annex 3), outside the context of public health emergencies.
- excludes data shared in the context of public health emergencies, including officially declared PHEICs under the *International Health Regulations (2005)*.
- excludes data and reports from clinical trials.<sup>11 12</sup>
- allows, but places no obligation on, WHO or Member States to collect, anonymize, analyse or share other health data than those already being collected, anonymized, analysed and shared.
- will not be applied retrospectively to data already provided by Member States to WHO, and/or which have already been shared by WHO with third parties.

#### Measures to ensure the ethical and secure use of data

Usually, the compilation, analysis and sharing of aggregated data (e.g. groups of patients or health facilities) does not raise ethical concerns or present risks with regard to

<sup>&</sup>lt;sup>10</sup> Please see WHO Information Note 21/2016 Public Disclosure of Results from Clinical Trials Funded or Otherwise Supported by WHO (4 July 2016)

<sup>&</sup>lt;sup>11</sup> WHO's existing position is that (i) all clinical trials are to be prospectively registered in a clinical trial registry meeting international standards (<a href="www.who.int/ictrp">www.who.int/ictrp</a>) and (ii) at a minimum a summary of results from the clinical trial are to be made publicly available within 12 months of study completion (<a href="www.who.int/ictrp/results/reporting">www.who.int/ictrp/results/reporting</a>)

<sup>&</sup>lt;sup>12</sup> Please see WHO Information Note 21/2016 Public Disclosure of Results from Clinical Trials Funded or Otherwise Supported by WHO (4 July 2016)

confidentiality. However, for data aggregates comprising small numbers of individuals, WHO will ensure that anonymity is preserved (i) by adopting standard security measures, (ii) by detailing how the data will be received by WHO, and (iii) by stating how the data will be shared (including the use of minimum numbers of patients).

In contrast, data on individuals (e.g. patients, survey respondents) provided by Member States may contain information that identifies those individuals. Therefore, data on individuals, and other information deemed sensitive (e.g. detailing specific locations or health facilities), will be made available by WHO to third parties only after the removal of identifying details following a formally verified anonymization procedure. <sup>13</sup>

Ethical obligations include but are not limited to (i) anonymization, and other tools to protect privacy and confidentiality, (ii) compliance with informed consent agreements in cases where informed consent is needed and respecting assurances to patients, research participants and other relevant parties about ways in which data (anonymized or otherwise) would be used, shared, stored or protected, and legitimate expectations such individuals may have about these standards, (iii) avoidance of stigmatization or exclusion of people or communities as a result of data collection, (iv) adoption of appropriate security measures to foster public trust. These should be considered and addressed before data transfer takes place. Any platforms established to share data should have an explicit ethical framework governing data collection and use.

Where resources permit, WHO will annotate, format and aggregate, or remove errors due to incorrectly spelled names, places and dates so as to increase data utility.

#### **Additional safeguards**

While the results obtained through use of the data should be considered a global public good, and serve the interests of public health, credit should be given to data providers, in addition to funding agencies and other contributors to the work.

As an additional safeguard to WHO, to Member States and to individuals, an independent data review committee will be established at WHO to consider, on a case by case basis and

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<sup>&</sup>lt;sup>13</sup> When primary data provided by Member States to WHO contain personal identifiers, an anonymization procedure is used, such as the anonymization of family names and any other names of patients are anonymized using the HASHBYTES function and SHA1 algorithm available in SQL. This removes any prefixes and encodes text so that it cannot be identified with the patient. After anonymization, the patients, their contact details and laboratory data can still be linked by authorized health workers/investigators in order to carry out further analysis. Anonymization procedures also eliminate any meta-data that could identify individuals.

in consultation with other relevant departments in WHO, any instances where the present policy provides inadequate guidance on data sharing.

#### Security of data held at WHO

Information security at WHO is based on the ISO 27001 standard.

WHO has formal and comprehensive information security policies with respective implementation guidelines. Policies cover information security, access to information and systems, cloud computing, application security, information classification and related security standards.

As international civil servants, all WHO staff are required to adhere to confidentiality as detailed in Staff Regulation 1.6.

## Statement of policy on data sharing

The terms and conditions of data transfer from WHO Member States are set out in Annex 4. These terms and conditions will be made available on the WHO website, and should accompany all data collection tools (paper-based, electronic or other) used by WHO to collect data from Member States.

#### Annex 1. EXAMPLES OF OPEN DATA POLICIES OF NATIONAL GOVERNMENTS

COUNTRY	OPEN DATA POLIC Y	OPEN DATA PORTAL	HEALTH	REPOSITORY LINK	TERMS OF USE	SPECIAL CONDITIONS AND LICENSE TERMS
Australia	Y	Y	Y	https://www.data.gov. au/	https://www.w.data.gov.au/about	<ul> <li>Material presented on data.gov.au is provided under a [Creative Commons Attribution 3.0 Australia licence]         (http://creativecommons.org/licenses/by/3.0/au/ "Creative Commons Attribution 3.0 Australia licence").</li> <li>Additional terms for use of material         When using content from this website that is licensed under a Creative Commons Licence, you are required to attribute the work in the manner specified in the licence (but not in any way that suggests that the publishing organisation endorses you or your use of the work).</li> <li>This website requires that you use the following form of attribution: Attribution to: Organisation name, jurisdiction, title of dataset, date the content was sourced, dataset URL</li> <li>Example: The Department of the Primary Industries and Regions, South Australia, Field Crop Estimates, Sourced on 22 July 2013, http://www.data.sa.gov.au/dataset/field-crop-production-estimates</li> </ul>
Austria	Y	Y	Y	https://www.opendata portal.at/	http://data. gov.au/abo ut	• [Creative Commons Attribution 3.0 Austria licence] (http://creativecommons.org/licenses/by/3.0/au/ "Creative Commons Attribution 3.0 Austria licence").
Belgium	Y	Υ	Υ	http://data.gov.be/en	http://data. gov.be/en/t erms-use	Unless otherwise specified you are free to use the information available on the Opendata Website free of charge.
Brazil	Y	Y	Y	http://dados.gov.br/		<ul> <li>Todo conteúdo licenciado sob uma Licença Creative Commons Attribution- ShareAlike 3.0 Unported. https://creativecommons.org/licenses/by-sa/3.0/deed.pt_BR</li> </ul>
Canada	Y	Y	Y	http://open.canada.ca/ data/en/dataset	http://open. canada.ca/e n/open- government -licence- canada	<ul> <li>Open Government licence – Canada</li> <li>You are free to: Copy, modify, publish, translate, adapt, distribute or otherwise use the Information in any medium, mode or format for any lawful purpose.</li> <li>You must, where you do any of the above: Acknowledge the source of the Information by including any attribution statement specified by the</li> </ul>

						Information Provider(s) and, where possible, provide a link to this licence. If the Information Provider does not provide a specific attribution statement, or if you are using Information from several information providers and multiple attributions are not practical for your product or application, you must use the following attribution statement: Contains information licensed under the Open Government Licence – Canada
Finland	Y	Υ	Υ	www.opendata.fi		
France	Υ	Υ	Υ	https://www.data.gouv .fr/fr/	https://www.data.gouv.fr/fr/terms/	<ul> <li>Les administrations de l'Etat et ses établissements publics administratifs publient systématiquement les données publiques en Open Data sous Licence Ouverte (permettant de reproduire, diffuser, adapter, et exploiter, y compris à titre commercial, sous réserve de mentionner la paternité). La Licence Ouverte s'inscrit dans un contexte international en étant compatible avec les standards des licences Open Data développées à l'étranger et notamment celles du gouvernement britannique (Open Government Licence) ainsi que les autres standards internationaux (ODC-BY, CC-BY 2.0).</li> </ul>
Greece	Υ	Υ	Υ	http://www.data.gov.g		Under the Open Data licence http://opendefinition.org/od/2.0/en/
India	Y	Υ	Y	https://data.gov.in/	https://data .gov.in/term s-of-use	Specific licence assigned to a dataset
Italy	Υ	Υ	Y	http://www.dati.gov.it/		Data is licensed under the CC BY licence
Japan	Y	Υ	Y	http://www.data.go.jp/ ?lang=english	http://www .data.go.jp/t erms-of- use/terms- of-use/	<ul> <li>Creative Commons Attribution 2.1 Japan http://creativecommons.org/licenses/by/2.1/jp/legalcode.</li> </ul>
Mexico	Y	Υ	Y	http://datos.gob.mx/	http://datos .gob.mx/libr eusomx	MX terms of free use of Open Government Data Mexico The present     "Terms of free use" promote the use, reuse and redistribution of open data sets in accordance with the following: You can:     Make and distribute copies of the data set and its contents; Disseminate and publish the data set and its contents; Adapt or rearrange the data set and its contents; Remove whole or in part the content of the data set; commercially exploit the data set and its contents, and; Create data sets

						derived from the dataset or its contents.
COUNTRY	OPEN DATA POLIC Y	OPEN DATA PORTAL	HEALTH	REPOSITORY LINK	TERMS OF USE	SPECIAL CONDITIONS AND LICENSE TERMS
Moldova	Υ	Y	Y	http://data.gov.md/en	http://data. gov.md/en/ terms-and- conditions	<ul> <li>reproduce, copy, publish and transmit it pursuant to the relevant legislation;</li> <li>disseminate and distribute it;</li> <li>adapt, modify, transform and extract data from it in order to create derived documents;</li> <li>exploit it for commercial purposes, for instance, by combining it with other documents or including it into your own product or application.</li> </ul>
Morocco	Υ	Υ	Υ	http://data.gov.ma/fr	http://data. gov.ma/fr/l a-licence	<ul> <li>De partager : copier, distribuer et utiliser la base de données. De créer : produire des créations à partir de cette base de données. D'adapter : modifier, transformer et construire à partir de cette base de données.</li> </ul>
New Zealand	Y	Y	Υ	https://data.govt.nz/	https://data .govt.nz/ter ms-of-use/	<ul> <li>Licence to reuse material on data.govt.nz does not cover the actual datasets Please note that the Creative Commons Attribution 3.0 New Zealand licence referred to above applies only to copyright material on data.govt.nz itself. It does not apply to the actual datasets themselves. data.govt.nz links to those datasets but the datasets themselves are not on this Site. They are on the websites of their source agencies.</li> <li>Re-use rights for the datasets themselves.The licences that apply to the datasets themselves (if any) are selected by the source agencies. Where we know the licence that applies to a given dataset listed on data.govt.nz, we endeavour to list it on this site. However, any questions regarding the licence applying to a given dataset should be directed to that dataset's source agency.</li> </ul>
Norway	Υ	Y	Y	https://data.norge.no/	http://data. norge.no/nl od/en	<ul> <li>Norwegian Licence for Open Government Data (NLOD)</li> <li>The licensee, subject to the limitations that follow from this licence, may use the information for any purpose and in all contexts, by: copying the information and distributing the information to others, modifying the information and/or combining the information with other information, and copying and distributing such changed or combined information.</li> <li>This is a non-exclusive, free, perpetual and worldwide licence. The</li> </ul>

						information may be used in any medium and format known today and/or which will become known in the future. The Licensee shall not sub-license or transfer this licence.
Philippines	Υ	Υ	Υ	http://data.gov.ph/		All content is in the public domain unless otherwise stated.
Portugal	Υ	Y	Y	http://www.dados.gov. pt/pt/inicio/inicio.aspx #sthash.Tr9i1Ogt.dpbs	http://www .dados.gov. pt/PT/Info/ AvisosLegais .aspx#sthas h.ZKt63Y6e. dpuf	<ul> <li>Terms of use, including the right to sublicense the same under the Creative Commons Attribution 3.0 license Portugal or any use that may replace (the current version of which can be found at http://creativecommons.org/ licenses/by/3.0/en/legalcode).</li> </ul>
Rep of Korea	Y	Y	Y	https://www.data.go.k r/e main.jsp#/L21haW 4=	https://ww w.data.go.kr /e subMain .isp#/L3B1Y nMvcG90L2 VuL0lyb3NH dWlkZWxpb mUkQF4wN iFtNiU=	Open data offered from open data portal is available to anyone in accordance with the law*, and can be freely used including the purpose of the profit. (Article 1, Article 3) *Act on Promotion of the provision and use of open data
Spain	Υ	Y	Y	http://datos.gob.es/	http://datos .gob.es/?q= aviso-legal	<ul> <li>Esta autorización conlleva, asimismo, la cesión gratuita y no exclusiva de los derechos de propiedad intelectual, en su caso, correspondientes a tales documentos, autorizándose la realización de actividades de reproducción, distribución, comunicación pública o transformación, necesarias para desarrollar la actividad de reutilización autorizada, en cualquier modalidad y bajo cualquier formato, para todo el mundo y por el plazo máximo permitido por la Ley.</li> </ul>
UK	Y	Y	Y	http://digital.nhs.uk/tr ansparency	https://data .gov.uk/ter ms-and- conditions	<ul> <li>The data and information available through data.gov.uk are available under terms described in the "licence" or "constraints" field of individual dataset records (meta-data). Except where otherwise noted this is the Open Government License.</li> <li>All dataset records (meta-data) published on data.gov.uk are licensed under the Open Government Licence.</li> </ul>
USA	Υ	Υ	Υ	http://www.healthdata .gov/	https://ww w.data.gov/	Public domain (US Govt Works)

## Annex 2. TERMS AND CONDITIONS FOR DATA-USE OF SELECTED AGENCIES

	Explicit open access	CC licenses	Specific	Permission	Commercial use
UNICEF	No No	Not mentioned	exemptions  "raw data"  "confidential information"	requests required  Yes, for everything except "personal use" and "educational purposes"	Not specified – see permissions
UNCTAD	No	No	Not specified	Yes, for everything	Not specified
UNODC	No	No	None mentioned	Not specified	Prohibited, as well as derivatives
World Bank	Yes	Yes	Information provided by member countries or third parties in confidence	Yes, if information is not in the databases or open knowledge repository	Prohibited, except for data
FAO	yes	No	3 <sup>rd</sup> party material	Yes, for commercial use of photos	Permitted
UNFPA	No	No	None mentioned	Yes, for any use other than for educational or other non-commercial purposes	Permission required
WIPO	Yes	Not mentioned	3 <sup>rd</sup> party material	No	Not specified
UNdata	Not explicit, but "All data and metadata provided on UNdata's website are available free of charge and may be copied freely, duplicated and further distributed provided that UNdata is cited as the reference."	Not mentioned	none	No	Not specified
OECD	yes	yes	Specific licenses for IAEA data and those from the Programme for International Student Assessment	Required for commercial use and translations	Permission required
IAEA	No	Not specified	Not specified	No	prohibited
ICRC	No	Not mentioned	None mentioned	Yes; no modifications allowed	prohibited
WHO	Not for data, but for externally published and BLT articles	Not for data, but for BLT articles	Not specified	For any use other than for educational or other non-commercial purposes.	Not specified – see permissions
UNESCO institute for statistics	For UNESCO publications, but not UIS databases	For publications, not data	3 <sup>rd</sup> party material	Not for "personal or public non- commercial," unless otherwise specified. Required for translation rights and commercial use.	Not specified – see permissions. Users required to include date of extraction when citing UIS data.

**Annex 3. DATA PROVIDED TO WHO** 

Data Types	Examples
WHO-supported household surveys	SAGE, STEPs, World Health Survey
Unit record mortality data Aggregated mortality data	(Not currently collected by HQ, but by PAHO) WHO Mortality Database
Aggregated health facility data	DHIS 2.0 data (Not currently collected by HQ, but hospital data collected by EURO)
Case-based health facility data	WHO Global Burn Registry data <sup>17</sup>
Health expenditure data	Global Health Expenditure Database (NHA Indicators)
Health facility surveys	Availability of drugs and diagnostics
Health research data (other than clinical trials) <sup>14 15 16</sup>	Case control investigations, prospective cohort studies
Key informant surveys	Existence of national road traffic laws
National survey reports	Prevalence of hypertension or tobacco use
Disease surveillance data	HIV prevalence in pregnant women or TB treatment outcomes

The World Health Report 2013: research for universal coverage, <a href="http://www.who.int/whr/2013/report/en/">http://www.who.int/whr/2013/report/en/</a>
 Statement by WHO on Public Disclosure of Clinical Trial Results (9 April 2015)
 WHO Information Note 21/2016 Public Disclosure of Results from Clinical Trials Funded or Otherwise Supported by WHO (4 July 2016)

<sup>&</sup>lt;sup>17</sup> Note: Case-based health facility data collection such as that in the WHO Global Burn Registry does not require WHO Member State approval.

Surveillance of notifiable diseases	Total cases of plague

#### **Annex 4. TEXT FOR INCLUSION IN DATA COLLECTION FORMS**

Data are the basis for all sound public health actions and the benefits of data-sharing are widely recognized, including scientific and public health benefits. Whenever possible, the World Health Organization (WHO) wishes to promote the sharing of health data, including but not restricted to surveillance and epidemiological data.

As used in this data collection tool, the term "Data provider" means a duly authorized representative of the governmental body with authority to release health data of the country to WHO (i.e. the Ministry of Health or other responsible governmental authority). The recipient of this data collection tool is responsible for ensuring that he/she is the Data provider, or for providing this data collection tool to the Data provider.

In this connection, and without prejudice to information sharing and publication pursuant to legally binding instruments, by providing data to WHO, the Data provider:

- confirms that all data to be supplied to WHO (including but not limited to the types listed in Table 1) hereunder have been collected in accordance with applicable national laws, including data protection laws aimed at protecting the confidentiality of identifiable persons;
- agrees that WHO shall be entitled, subject always to measures to ensure the ethical and secure use of the data, and subject always to an appropriate acknowledgement of the country:
  - to publish the data, stripped of any personal identifiers (such data without personal identifiers being hereinafter referred to as "the Data") and make the Data available to any interested party on request (to the extent they have not, or not yet, been published by WHO) on terms that allow non-commercial, not-for-profit use of the Data for public health purposes (provided always that publication of the Data shall remain under the control of WHO);
  - to use, compile, aggregate, evaluate and analyse the Data and publish and disseminate the results thereof in conjunction with WHO's work and in accordance with the Organization's policies and practices.

Except where data-sharing and publication are required under legally binding instruments (International Health Regulations (2005), WHO Nomenclature Regulations 1967, etc.), the Data provider may in respect of certain data opt out of (any part of) the above, by notifying WHO thereof in writing at the following address, provided that any such notification shall clearly identify the data in question and clearly indicate the scope of the opt-out (in reference to the above), and provided that specific reasons shall be given for the opt-out.

Director Strategy, Policy and information (SPI)
World Health Organization
20, avenue Appia
1211 Geneva
Switzerland