

Health Statistics Dissemination Principles



HEALTH STATISTICS DISSEMINATION PRINCIPLES

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1. HEALTH STATISTICS AND PUBLICATION

The Department of Health Statistics of the National Institute for Health Development (NIHD) operates as a central unit, collecting health and healthcare related statistics in Estonia.

The mission of the Department of Health Statistics of NIHD is ensuring public health and welfare through better statistics and information.

The Department of Health Statistics of NIHD builds on the Official Statistics Act and produces health statistics as official statistics. Official statistics is public information and thus a part of the infrastructure of a democratic society.

Official statistics:

- is produced for the benefit of the society;
- is equally accessible to all
- is funded by the state budget;
- is produced under the official or European Union statistical programme;
- enables consumers of statistics make the necessary decisions;
- · complies with internationally recognised quality indicators.

In addition to producing statistics, another important part is forwarding the statistics to its consumers i.e. distribution.

1.1 Areas of health statistics and data sources

Health statistics comprises the state of health and health behaviour of the population, use of health services as well as health resources and their use. The statistics of causes of death, births and miscarriages are also presented under health statistics. The health statistics has a common element with the statistics regarding the population, social protection, welfare services, occupational health and other areas.

The data sources for health statistics are various registers and databases In collecting and publishing of data, co-operation is carried out within the National Institute for Health Development between different departments, with other state authorities, professional societies and associations as well as with international organisations.

In addition to distributing statistics produced by the National Institute for Health Development, we also distribute health related statistics of other data-collecting authorities using the Health Statistics and Health Research Database (http://pxweb.tai.ee/esf/pxweb2008/dialog/statfile1.asp). The Department of Health Statistics of NIHD does not carry out additional data-processing for data of other authorities.

1.2 Health related statistical products and services

Official statistics is a product that is the result of data processing based on the data collected during official statistical surveys i.e. statistical work. The term "service" is used in addition to the product when the single consumer is involved in the completion of the statistical output, and the outcome is created and reaches the consumer as a result of data processing carried out by the

employees of the National Institute for Health Development (contract work). In ordering a service, the product i.e. statistics is forwarded to the consumer.

The products is forwarded via a data medium (PDF, HTML or Excel file) through various marketing channels (Health Statistics and Health Research Database, website, prints).

The Department of Health Statistics offers various products and services to the consumers:

- Regular publishing of statistics in the Health Statistics and Health Research Database (data tables);
- Figures and charts
- Press releases
- Analyses:
- Publications (prints and electronic publications);
- Answering health statistics related information requests;
- Advising respondents (user support of the data reporting channel A-Veeb);
- Enabling the data subject to access information regarding themselves;
- Contract work (additional data processing based on our collected data);

The data table is the primary output of official statistics, reaching consumers via different data mediums and marketing channels. Meta data and graphic materials included in the data table are also considered to be a product. As the two aforementioned products are not separately offered to consumers, they have not been added to the product list.

A press release is information, equivalent to news, consisting of data based on the most recent official statistics, which aims at informing the public on the development and availability of certain areas of health statistics. Press releases are published on the NIHD website, on the main page of terviseinfo.ee, on the NIHD Facebook page, and are forwarded to journalists via e-mail. The remaining consumers may subscribe to the RSS news feed of the NIHD website, enabling them to receive a respective notice on their e-mail when a press release is published.

Analyses and publications are published as prints or e-publications. Due to the target group needs, most publications are bilingual i.e. published in Estonian and English. Publications in other languages are custom-made. All health statistics publications issued in print shall be given an International Standard Book Number – ISBN).

Request for information is a request for accessing explanations on published or documented information and a request for locating the requested information. It shall be completed in Estonian or in English. A request for information enables to get information on health statistics, the collection and publication of which the Department of Health Statistics is responsible for. Also, consumers shall be advised on finding other health statistics related information. A request for information concerning statistics on one institution has to be submitted along with the respective institution's official written clearance for issuing the data. Otherwise the request for information is not satisfied.

Generally, a request for information is answered within five consecutive days starting from the following day after the request for information has been registered. Where it is found that the request for information requires the carrying out a survey, adapting a new methodology, extra data processing, analysis or other additional resources, the request shall be regarded as a contract work which is charged and the ordering terms and conditions of which are established in section 1.4. In this case the person requesting the information shall be informed on the cost of the service.

If the request for information cannot be satisfied, we shall inform the requesting person about it within five consecutive days to specify the request. Requests for information may be made on the website of NIHD (activities→ health statistics → request for information). All questions shall be answered by the Head of the Department of Health Statistics.

Charged contract work, the completion of which requires carrying out a survey, adapting a new methodology, extra data processing, analysis or other additional resources is established in section 1.4.

Advising respondents. Respondents can contact the statisticians of the Department of Health Statistics regarding questions and issues relating to the completion of reports. Where needed, area analysts will ensure additional consultation. Advice regarding the use of the electronic data reporting environment A-Veeb shall be provided by the statisticians of the department as well as the analysts. The contact information of the statisticians and analysts of the department is available in the electronic data reporting environment.

Enabling the data subject to access information regarding themselves. The respondents have the right to access information collected on them by the National Institute for Health Development. The former is based on the Official Statistics Act (§ 28(6)) and the Personal Data Protection Act (§ 19). To access one's own information, a person with powers of representation to the authority shall submit a request with respective data, the list of which is given on the website of NIHD (activities \rightarrow health statistics \rightarrow request for information \rightarrow accessing own information). A (digitally) signed request must be forwarded via e-mail to tai@tai.ee or signed by mail at Hiiu 42, 11619 Tallinn. The request shall be completed within five consecutive days.

In case the request cannot be satisfied due to inadequate information, we shall contact the person requesting the information within five consecutive days to specify the data. All due dates of proceedings are calculated starting from the consecutive day following the registration of the request. The data subject shall receive a copy of the information regarding him/her via e-mail encrypted by the public certificate of the contact person's ID-card.

1.3 Marketing policy

The Department of Health Statistics of the National Institute for Health Development uses the following marketing channels to market products and services:

- E-mail;
- Health Statistics and Health Research Database;
- NIHD website (and RSS news feed)
- Information days, training, conferences;
- Social media (Twitter, Facebook).

The function of mass mailing via <u>e-mails</u> is forwarding press releases, contacting target groups and forwarding product information.

The aim of the <u>Health Statistics and Health Research Database</u> is to make health statistics accessible on the Internet and group the statistics of one area into a single joint dataset where users could easily find and use data. The database is public and free of charge. In addition to new statistical information, the database also includes data from previous periods dating as far back as possible, and the database is regularly updated. An English version of the database is also available.

Updating the database with new or unpublished data is coordinated with the working group of the database, convened by the head of the working group and the composition of which is specified under order No. 1-4/93 of the Director of the National Institute for Health Development of 18.12.2012 "Appointing members of the Health Statistics and Health Research Database working group." The work of the working group is regulated with order No. 1-4/89 of the Director of the National Institute for Health Development of 14.01.2013 "Rules of procedure of the Health Statistics and Health Research Database working group." The terms and conditions of data to be added to the database and the rules of procedure of adding them is specified under order No. 1-4/87 of the Director of the National Institute for Health Development of 14.01.2013 "The rules of procedure of

adding new data to the Health Statistics and Health Research Database of the National Institute for Health Development" (available on the website of NIHD).

The objective of the <u>NIHD</u> website (<u>www.tai.ee</u>) is to raise awareness of the public on the existence and accessibility of health statistics and offer electronic products and services to a wide range of users. The website is accessible in Estonian as well as in English. In addition to statistics collected by the National Institute for Health Development, the website also contains references to other websites of authorities producing health related statistics and to international databases.

<u>Information days, training, conferences.</u> The products of health statistics are introduced on information days, training and conferences of NIHD and other cooperation partners in which the participants are the potential consumers of health statistics.

In <u>social media</u> (Facebook, Twitter), notices on new health related statistical products are published on the day the product is launched. Generally, a short introductive overview is added to the publication notice.

1.4 Contract work and price policy

Official statistics is considered a public product that is accessible free of charge. Additional processing of data (contract work) is charged, covering the expenses of work done outside the working plan and budget. The selling of services does not grant profit.

<u>Charged contract work</u> is a request for obtaining more detailed information than is provided in the NIHD public database, press releases or statistical publications or, when satisfying the request requires conducting a survey, adopting a new methodology, additional data processing or carrying out an analysis. Data is generally obtained by processing information from the source database. Contract work is also considered preparing statistics upon the request of the client, taking one or more hours to complete. Contract work also includes the systematic presenting of data according to the request of the consumer.

Adding new indicators to the dataset performed as contract work is completed according to the list of statistical work. The list of statistical work is confirmed for a 5 year period; suggestions are advised to be made in sufficient time. More detailed statistics can be requested for all areas of health statistics.

The prices of contract works completed under the health statistics work do not include expenses made for obtaining already published statistics. The price depends on the time it takes to process data in detail and is calculated by the hour. The contract work shall be completed in Estonian or in English and forwarded to the client electronically.

<u>Due date for completing contract work.</u> After receiving a contract work and after specifying the content of the work, the NIHD shall forward an invoice to the client. A contract work is generally completed within ten consecutive days after the receipt of the payment. In case the work cannot be completed within ten consecutive days, the client shall be informed. A contract work shall not be accepted from a client who has failed to pay for the previous contract work.

Ordering a contract work. Contract works may be ordered by completing the request form on the website of NIHD (activities \rightarrow health statistics \rightarrow request for information). All questions shall be answered by the Head of the Department of Health Statistics.

Forwarding complaints and suggestions regarding contract works. All written complaints and suggestions regarding contract works shall be registered in the NIHD document management system. Less complex complaints shall be resolved at the earliest opportunity; in the case of more complex complaints, a notice shall be given on when it will be possible to resolve the complaint. The Head of the Department of Health Statistics of NIHD is responsible for resolving all complaints. All complaints made via mail or e-mail shall be answered in written form. Complaints are answered within ten consecutive days after registering the complaint. If answering the complaint requires

additional information, the deadline may be extended to 30 days. Suggestions and complaints can be submitted to the Head of the Department of Health Statistics via e-mail.

2. PRINCIPLES FOR DISTRIBUTING HEALTH STATISTICS

Distributing health statistics comprises publishing statistics i.e. making statistics publicly accessible, forwarding statistics and incorporating marketing activities in distributing statistics to consumers.

2.1. Publication principles

In publishing and distributing official statistics the following principles are observed:

- 1. All consumers must be granted **equal access** to health statistics. This means giving notice regarding the publication dates of statistics and observing deadlines no consumer category (including Eurostat, state authorities and media) is given access to statistics before the publication date.
- 2. The health statistics is **first published** in the <u>NIHD public Health Statistics and Health Research Database</u>, where figures are published. If a press release is also published, it shall be published simultaneously with the first publication of data in the database. Information provided in the statistical publications is generally published later.
- 3. Distributing health statistics is **impartial and transparent**, meaning that statistics are not subject to any political comments or comments from state authorities.
- 4. Health statistics is a **public product** the production of which is funded from the state budget. It is therefore free of charge for consumers. The consumer of statistical products only covers direct expenses related to the distribution of statistics after production (printing, mailing).
- 5. In the case of an **erroneous interpretation or misuse** of health statistics, a reply or comment shall be published.
- 6. Press releases regarding statistical data of interest to the public shall be published. Press releases and publications shall use data from the NIHD public database. This is done to ensure that identical data is distributed to consumers using various channels. If our published data differs from data published by other public sources, an explanation shall always be added, specifying the difference.
- 7. According to applicable laws, **confidentiality** is ensured upon publishing health statistics and **data protection** is guaranteed upon processing data. Information that is public prior to publication shall not become confidential if used for statistical purposes. Distributing data of this kind does not infringe the requirement of confidentiality.
- 8. The health statistics to be published is equipped with **meta data** and unambiguous explanations to avoid erroneous interpretation and misuse. The minimum set of meta data required for correctly interpreting the statistics and which is published by the NIHD Department of Health Statistics consists of the following:
 - a) Title of the table, which, depending on the subject, usually comprises the researched cases and presented age groups, geographic specifications, observation unit, etc.;
 - b) Titles of columns and rows in tables;
 - c) Measuring units:
 - d) Definition of time/period;
 - e) Regional entities;
 - f) Comparability in time (including breaks in time series);
 - g) Footnotes referring to specific recommendations;
 - h) Information on the data source (type of data source, data collection specifications);

- i) Information on the restrictions of using statistics;
- j) Date of last update;
- k) Definitions of terms needed for interpreting data;
- I) Classifications used.

2.2. Quality requirements of statistics

The work of the National Institute for Health Development in collecting, analysing and publishing health statistics is in compliance with international methods and corresponds to the principles of impartiality, reliability, profitability, confidentiality and transparency.

The official statistics is different from general statistics due to the fact that it is subject to international quality requirements observed by all producers of official statistics in all states and international organisations. All products and services of official statistics are therefore based on the following quality requirements:

- Impartiality;
- Reliability;
- Timeliness;
- Profitability;
- Confidentiality;
- Transparency.

<u>Impartiality</u> is the objective and impartial means of producing statistics which does not contain any political pressure or pressure from other interest groups – especially regarding technical techniques, definitions and methodology for reaching the established objectives. It is also related to the accessibility of statistics with a minimum standstill period for all consumers.

Reliability is the ability of the statistics to faithfully reflect the reality which the statistics must represent according to its objective. It also means that in choosing sources, methodology and procedures, scientific criteria are used. Any information regarding coverage, methodology, procedures and sources increases the reliability of data.

<u>Timeliness</u> means that the production of statistics is based on clearly defined objectives and its necessity to the consumers. The needs of the consumer define the areas, timeliness and scope of the statistics – whereas new demographic, economic, social and environmental developments are always regarded. Data is only collected to the extent necessary to achieve the desired results. Producing statistics that is no longer interesting based on the set objectives should be waived.

<u>Profitability</u> means the optimal use of all available resources and minimising the burden on the respondents.

<u>Confidentiality</u> means protecting data regarding single statistical units that have been obtained directly or indirectly from administrative or other sources for statistical purposes from breaching any rights to confidentiality. This means impeding the illegal and non-statistical use of obtained data.

<u>Transparency</u> means the right of the respondents to obtain information on the legal basis, objectives of data collection and safeguards to be implemented.

2.3 Legal acts serving as a basis for production and distribution oh health statistics

 The collection and publication of health statistics is based on the <u>Health Services</u> <u>Organisation Act</u>.

- The dissemination guidelines of health statistics are based on the Official Statistics Act, Regulation (EC) No 223/2009 of the European Parliament and of the Council on European statistics and the European Statistics Code of Practice.
- The principles of the dissemination and publication of statistics are based on the <u>Official Statistics Act</u>, on the <u>Special Data Dissemination Standard</u> and on the <u>European Statistics</u> Code of Practice.
- The IMF Special Data Dissemination Standard (SDDS) which Estonia has pledged to observe establishes that prior notification of at least three months regarding the publication dates is required. Thus, the NIHD publishes a release calendar by 1 October via press releases and the database with exact dates for the upcoming year. The objective of these actions is to prevent being accused of interfering in politics and informing the consumer on when the statistics may be used i.e. help the consumer in planning his/her work. In addition, prior notification of the publication dates allows to ensure the equal treatment of consumers, granting them simultaneous access to official statistics.
- The publication and distribution of statistics as public information is also indirectly regulated by the <u>Public Information Act</u>.
- The structure and content of collected data is established by the Regulation of the Minister of Social Affairs "Requirements for the compilation of reports on health statistics and health related economic activities, data composition and order of submission".
- Data protection is based on the Personal Data Protection Act.

3. CONSUMERS OF HEALTH STATISTICS

The consumers of health statistics are all legal and private persons who need health related statistics for making professional decisions or are interested in health related statistics.

On the basis of the consuming activity of statistics and/or on the importance of customer relations (participation in the production process, distribution of statistics to a broad public, use of statistics for making decisions that have an impact on the society), the main consumer segments are the following:

- Ministries, state authorities and politicians;
- Local governments;
- Research and education institutions, libraries;
- Media:
- Professional associations in the area of health; professional societies, non-profit associations, etc.;
- International organisations WHO, OECD;
- Eurostat and other statistical organisations;
- · Providers of health care services;
- Citizens;
- Survey companies;
- Pharmaceutical companies.

4. DISTRIBUTION OF HEALTH STATISTICS

4.1 Publication times

The publication dates of health statistics are announced with the help of the release calendar on the NIHD public website, available for users on the website of the database.

As of 01.01.2014, all data in the database is available for consumers on the date announced in the release calendar at 10.00. All important data updates are announced on the NIHD website, the website of the database and in social media (NIHD Facebook page, database Twitter page).

Press releases are published on the announced date at 10.00. The information given in press releases is simultaneously published in the database of health statistics. Electronic versions of all publications are made accessible on the NIHD website free of charge on the publication date at 10.00.

Should a change occur in the publication date, the right publication date and time shall be specified in the release calendar.

In the beginning of October (generally on 01.10), the publication dates of statistical products for the upcoming year are announced in the release calendar. The release calendar is confirmed by the Director of NIHD and amendments by the Head of the Department of Health Statistics.

In case any data is updated, the date of the last update shall be added to the table. In case data is corrected, information on the content and reasons shall be given in notes under the table. The footnotes of the table show all corrections and amendments made in the past year.

4.2 Notification of corrections

<u>Correcting data tables.</u> All corrections made to data tables are reflected as footnotes under the table in the database. Notes regarding corrections are stored for one year after making the corrections.

Initial data is only published in areas where it is relevant to ensure the timeliness of the statistics. Initial data is always followed by the publication of final data.

The release calendar states two separate publication dates for the publication of initial and final data. In the case of initial data, a note indicating "initial data" shall be given in the release calendar. In the case of final data, no special note is given. In publishing initial data, a note shall be given next to the table, e.g. "2010 data is initial". In the publication of final data, the note shall be removed.

No corrections shall be made to initial data, except for when a mistake may lead to the broader public to incorrectly interpret the statistics. Initial data shall be replaced with final data on the date specified in the release calendar.

When needed, final data shall be corrected within five years from the publication date, except for recalculation regarding data revision, updating methodology, etc.

<u>Correcting press releases.</u> In case of errors in press releases, the NIHD shall issue a correction, stating in which part of the text or table the error occurred along with a request to consider the new sent data correct. A notice shall be announced on the main page of the website, stating the date of the correction.

<u>Correcting publications and prints.</u> Corrections are only made in databases and electronic publications; in printed publications, corrections are not made. Depending on the significance of the error, the public may be notified via the NIHD website. The note "corrected on dd.mm.yyyy" shall be added to the description page of the publication. In the database, the note "Data has been corrected on dd.mm.yyyy" shall be added under the table.

Should the health statistics data be incorrectly interpreted, the NIHD shall notify the public on the false interpretation.

The data users are liable for errors relating to the use and further processing of data.

4.3 Data protection

In publishing statistics, confidentiality is granted, i.e. data is published or forwarded without any characteristics that would allow to identify the data subject, as consolidated data of at least three data subjects (whereas the share of data of any data subject does not exceed 90%), except for regional data. Upon the written consent of the data subject, the data of the data subject shall also be published, e.g. of the data obtained from hospitals included in the development plan of the hospital network, we publish indicators for each hospital in the database.

Publishing survey data is based on the principle that the standard error may not exceed 25% of the value of the indicator. The survey data is weighted to the population.

<u>Data protection in the case of contract works.</u> For using data that contains indirectly identifiable personal data collected via eHealth, a respective application must be submitted to the Tallinn Medical Research Ethics Committee and the Estonian eHealth Foundation. If data containing indirectly identifiable personal data requires additional processing by the analysts of the NIHD Department of Health Statistics, the respective request for information or contract work as well as the approval from the Tallinn Medical Research Ethics Committee and the Estonian eHealth Foundation must be submitted to NIHD. An approval from the Ethics Committee and the Estonian eHealth Foundation is not required if the contract work does not entail indirectly identifiable personal data.

4.4 Referring to data sources and copyright protection

All products of the NIHD health statistics are objects subject to copyright and are protected by the Copyright Act. Although all rights are applied to the author from the moment of creation of the work and there is no need to refer to copyrights, all publications of health statistics include the following note: "When using or quoting the data included in this issue, please indicate the source". All publications are labelled with the NIHD logo.

The consumer may make copies of statistical publications for his or her own use but they may not be used for commercial purposes. In using any NIHD data publicly, the NIHD must be referred to.

Referring to data published in the NIHD public database. In the case of data tables published in the NIHD database, it is recommended to first refer to the data source (e.g. the Estonian Causes of Death Registry) and then to the channel of the published data and the date of use (NIHD Health Statistics and Health Research Database, table SD21, as at 31.12.2013). When referring to data from a registry under the NIHD or from a study conducted by NIHD, a reference must be made to NIHD as well as to a more specific source (e.g. Health Behaviour among Estonian Adult Population, year of study, National Institute for Health Development).

<u>Should the NIHD use data collected by other authorities</u>, references to data sources in the output (publication, database, etc.) shall be made as follows:

- In the database, the data source is referred to under each table and under the definitions and methodology.
- In publications, a data source reference is not added to a table, figure or thematic map, if the
 statistics is collected by the NIHD. A source is then referred to in the methodology or added
 to the publication's list of references. If another data source is used, a reference shall be
 made under the respective table, figure or thematic map. If a figure is based on data from a
 foreign source (e.g. Eurostat) and on data from the NIHD, a reference shall also be made to
 NIHD.

4.5 Forwarding data to international organisations

The NIHD Department of Health Statistics regularly forwards health and health care related statistical data to the following international organisations:

- Eurostat database:
- The WHO Health for All database;
- OECD database.

References to these databases are available on the NIHD website.

Data shall be forwarded to Eurostat (Article 21 of the regulation on European statistics, page 172) via a special protected channel for forwarding confidential data (EDAMIS).

5. COLLECTION OF FEEDBACK

The health related statistical products and services must comply with consumer needs which may change in time. Therefore the needs must regularly be monitored and the statistical products and services developed when needed.

The NIHD regularly monitors consumer needs. A majority of the information on statistical needs is obtained through the cooperation with main consumers; statistical work is also coordinated with the statistics consumers. Feedback shall also be collected from consumer and respondent training. A health statistics user survey is carried out every three years. The use of the Health Statistics and Health Research Database is annually monitored and feedback is collected using the feedback form on the website of the database.

The decision on which statistical products and services are practical to be compiled based on data collected during the statistical work shall be made according to the relevance of the respective product or service to the target group as well as to the preferences of the consumer, e.g. in which form and what kind of statistics are to be used. Best practices of other countries shall also be observed.

The production of statistical products and services shall be terminated when there is no longer need for the area in question or when data on the respective subjects are no longer available.

Note: The Health Statistics and Health Research Database has been created under the "Promoting Healthy Choices and Lifestyles 2008–2009" and "Promoting Healthy Choices and Lifestyles 2010–2011" programmes of the European Social Fund.

Compiled on: 24.10.2014

Health and health care statistics:

Health statistics and health research database

http://www.tai.ee/tstua

Website of Health Statistics Department of National Institute for Health Development

http://www.tai.ee/tegevused/tervisestatistika

Dataquery to National Institute for Health Development

tai@tai.ee

Database of Statistics Estonia

http://www.stat.ee/

Statistics of European Union

http://ec.europa.eu/eurostat

European health for all database (HFA-DB)

http://data.euro.who.int/hfadb/

OECD's statistical databases (OECD.Stat)

http://stats.oecd.org/index.aspx?DataSetCode=HEALTH STAT