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HA4. Standardisation methods of the collection of health information

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I. Introduction

Health information is used to monitor health and diseases, health determinants, and cost and quality of health care in the population and population sub-groups, to support policy making, for planning and evaluation of prevention programmes, research and health education. For reliable conclusion and benchmarking between countries/regions, it is essential that the information used is comparable and representative for the target group as well as of high quality and reliable. These can be ensured with proper standardisation and harmonisation of data collection.

II. Background

A. Standardisation and harmonisation

Standardisation can be defined as the process of reaching agreement on common data definitions, formats, representation and structures of all data layers and elements (United Nations 2000). According to the International Organization for Standardization, standards are documented agreements containing technical specifications or other precise criteria to be used consistently as rules, guidelines, or definitions of characteristics to ensure that materials, products, processes, and services are fit for their purpose (<http://www.iso.org/iso/home/standards.htm>).

Standards can be legally binding (contracts, laws or regulation), *de jure* standards, based on informal convention or dominant usage, *de facto* standards, or *voluntary* standards which are published and available for people to use.

Standardisation can help to maximize comparability, interoperability, safety, repeatability and quality (<https://en.wikipedia.org/wiki/Standardization>) of collected information.

Harmonisation is a generic term for procedures that aim at achieving or at least improving, the comparability of different data collections, such as surveys and official statistics. The concept of harmonisation is closely related to that of standardisation. In surveys, harmonisation procedures may be applied in any part of the survey life cycle, and can be related to the study design, choice of indicators, question wording, translation, adaptation, questionnaire designs, sampling, field work, data coding, data editing, or documentation.

Two general harmonisation strategies can be distinguished: input harmonisation and output harmonisation:

1. *Input harmonisation* aims to achieve standardised measurement processes and methods in all national or regional populations. Comparability is realized through standardisation of definitions, indicators, classifications, and of technical requirements (Survey Research Centre 2011). In an ideal case, this means that all countries use precisely the same data collection procedures. Country-specific particularities are only permissible when indispensable -for example in the language used on the questionnaire (Roland 2003, Eurostat 2016).

2. *Output harmonisation* aims to determine the goal – or the value surveyed. The selection of suitable data collection methods is left to the countries themselves. In general terms, output harmonisation sets an international concept that defines the circumstances for data collection. The task of working out suitable national concepts and data collection procedures with which the international concepts can be portrayed is then left to the countries. These measurements need to be cross-validated into a unified measurement scheme. (Survey Research Centre 2011; Roland 2003, Eurostat 2016)

In practice, mixed forms of input and output harmonisation exist in many cases of data collection.

B. Why are standardisation and harmonisation needed?

The need for standardisation and harmonisation arises when results obtained from collected data are compared within country/region/sub-group over time or between countries/regions/sub-groups. The aim is to eliminate factors that might limit the comparability.

In the following, some examples demonstrating the need for standardisation and harmonisation are presented.

Health examination surveys:

Several physical measurements conducted in health examination surveys are rather sensitive for the deviations in the measurement protocols and there are also differences between measurement devices which may compromise comparability of the results.

For example blood pressure may vary up-to 30 mmHg depending on details of the measurement procedure (Tolonen H et al 2015):

Factor	Effect on systolic blood pressure	Effect on diastolic blood pressure
Cold room vs. comfortable room temperature	↑ 14 mmHg	↑ 15 mmHg
Smoking before measurement	↑ 10 mmHg	↑ 8 mmHg
Not resting at least 5 min before measurement	↑ 10-20 mmHg	↑ 14 mmHg
Left arm vs. right arm	↓ 1-3 mmHg	↑ 1 mmHg
Back/feet unsupported vs. supported	↑ 5-15 mmHg	↑ 6 mmHg
Taking during the measurement vs. silent	↑ 17 mmHg	↑ 13 mmHg
Cuff too large	↓ 10-30 mmHg	↓ 10-30 mmHg
Cuff too small	↑ 3-12 mmHg ↑ 30 mmHg among obese	↑ 2-8 mmHg ↑ 30 mmHg among obese

Similar effects can be seen for total cholesterol measurement in relation to posture of the subject during the sample collection, use of tourniquet, type of blood sample (serum or plasma) etc. (Tolonen et al 2005)

Health interview surveys:

For questions intending to measure the same phenomena, different wordings, additional clarification or variation in answer categories are known to exist.

For example a simple question about perceived health “How is your health in general?” is known to have several different answer alternatives: ‘Very good, good, fair, poor, very poor’ and ‘Excellent, very good, good, fail, poor’. (OECD 2011)

Another example is related to the awareness of hypertension where two main formats of question are used “Have you ever been told that you have high blood pressure” and “Have you ever been told by a doctor or other health worker that you have high blood pressure”. (Saarela 2011)

Without standardisation, this type of deviations in the question format may compromise the comparability of results between surveys.

For standardisation of questions, a proof of *reliability* and *validity* must be done. *Reliability* or repeatability is verified if the participant is giving repeatedly equal answer to the same question (example: apartment size in square meters or nutrition habits). The *validity* or correctness of the answer is verified if the participant gives the correct answer. The questions and their answers have to be verified by experts (example: to check apartment size, textiles and floor coverings with focus on containing substances of interest by experts, doctors concerning illnesses etc.). Questions and the options to answer have to be as clear as possible. All optional actions shall minimize misclassification. To enable comparing results in a long-term or repeated study, it is necessary that questions keep the exact wording and the answer categories do not change over time.

If a study covers different countries it has to be assured that questions are *harmonized* and properly translated. Differences in answers should only reflect differences between the countries.

Routine/administrative data sources:

Comparing healthcare performance between countries and regions could be based on routinely collected data, e.g. hospital patient registers. For example when comparing healthcare use of heart failure patients, definition of which patients to include could be based on diseases classification system including the International Classification of Diseases (ICD) where different countries use different versions. This leaves work to cross-validate the diagnostic systems between countries. The healthcare use could include bed days in hospital or number of procedures used, where standardisation between countries is necessary.

Without output harmonisation, differences between countries, classification systems and coding practices, makes the comparison obsolete.

III. Aim

The aim of this paper is to identify the existing level of standardisation and harmonisation of health information collected in EU through ongoing/completed EU funded projects and EU/international organisations. This will also facilitate the identification of possible areas where standardisation and harmonisation procedures are still missing.

IV. Approach

A questionnaire relating to the horizontal activities was mailed to 23 persons in November 2015. The questionnaire included the following questions about standardisation methods used for the collection of health information:

1. In your area/project, have you collected individual/aggregated level data of health information?
 - a. If yes, have you used standardized protocols for data collection?
 - b. If yes, what level of standardization has been used? (Data collection, forming of reported indicators, etc.)
2. What kind of limitations/obstacles can you see (in your area/project) for standardization of data/health information collection?

A reply was obtained from 19 persons.

Information was also obtained from project web sites when available and through personal contacts.

V. Results

A. Available standardisation and harmonisation procedures for collection of health information

The collection of health information can be divided in to primary and secondary data collection. Primary data collection means cases where data are primarily collected for this specific use (surveys or population based disease specific registers). Secondary data collection means that the data used were originally collected for some other purpose such as routine registration (e.g. hospital patient registers) and further used for other, secondary purposes.

Previous and ongoing EU funded projects on health information have used widely different levels of standardisation and harmonisation procedures to guide their health information collection (Table 1). When projects have focused on primary data collection input standardised procedures have been developed. When collection of health information relies on to secondary use of routine/administrative data, which is collected as part of national/regional activities, often regulated by national laws, output harmonisation of collected data items can be done.

The EU and international organizations such as WHO and OECD are commissioning both primary data collection and the use of already nationally collected data for secondary purposes. (Table 2.)

Table 1. Used standardisation and harmonisation procedures by EU funded projects

EU Project	Collection tool	Primary or secondary data collection	Input or output harmonisation	Procedure for	Reference
EHES	Population based health examination survey	Primary	Input	<p><i>Standardized protocols</i> for measurements of height, weight, waist circumference and blood pressure, and collection of blood samples and questionnaire for collection of background information, health behaviours and health information related to measurements listed above.</p> <p>Also <i>guidelines</i> for sample size and sampling, recruitment, legal and ethical issues, and many aspects of fieldwork, as well as for quality control activities were prepared.</p>	Tolonen H (2013a, 2016a) Tolonen H (2013b, 2016b)
			Output	<p><i>Definition of data items</i> to be transferred to the central database and key indicators to be reported</p>	Tolonen H (2013c, 2016c)
COPHES/ DEMO-COPHES	Examination surveys	Primary	Input	<p><i>Standardized protocols</i> for questionnaires and sample collection (hair and urine).</p> <p><i>Guidelines</i> for recruitment, performance of fieldwork, and quality control activities were prepared.</p>	Becker et al (2014) Casteleyen et al (2015) Esteban et al (2015) Exley et al (2015) Fiddicke et al (2015) Schindler et al (2014)
Euro-Peristat	Different data sources	Secondary	Input/Output	<p><i>Standardized instrument</i> to collect aggregated level data</p> <p><i>Definition</i> of indicators collected about perinatal</p>	Euro-Peristat (2012)

				health	
JA-ECHIM	Different data sources	Primary/Secondary	Input/Output	<i>Definition of indicators</i>	Verschuuren (2013)
EuroSafe / IDB	Routine/ administrative data sources	Secondary	Input	<i>Standardized definitions</i> for coding injury cases for IDB	EuroSafe (2014)
EUROCISS	Disease register data	Primary	Input/Output	Standardized procedure for collection of data on acute myocardial infarctions at the population level	Madsen (2007)
			Input/Output	Standardized procedure for collection of data on stroke at the population level	Giampaoli (2007)
	Health examination survey	Primary	Input	Standardized procedure for risk factor measurements and standardized questionnaire for resent measurements, awareness and treatment of diseases, and family history.	Primatesta (2007)
EUROHOPE	Routine/ administrative data	Secondary	Output	Standardized definition for extracting acute myocardial infarctions from the national registers.	EuroHOPE (2012a)
			Output	Standardized definition for extracting strokes from the national registers.	EuroHOPE (2013)
			Output	Standardized definition for extracting breast cancer from the national registers.	EuroHOPE (2012b)
			Output	Standardized definition for extracting infants with very low birth weight and very low gestational age from the national registers.	EuroHOPE(2012c)
ECHO	Routine/ administrative data	Secondary	Output	Definitions for included variables and coding of variables. Cross-validation of diagnostic and procedure codes.	Bernal-Delgado (2015)
ENRIECO/ OBELIX	Survey	Primary	Input	ISAAC questionnaire for asthma & allergies	

Table 2. Used standardisation and harmonisation procedures by EU/international organisations

Organisation	Collection tool	Primary or secondary data use	Input or output harmonisation	Procedure for	Reference	Format of standard
Eurostat	Survey	Primary	Input/Output	Manual for planning and implementing the 2 nd waver of the European Health Interview Survey (EHIS). Including conceptual guidelines, model questions and translation and interview instructions. The second part deals with statistical survey guidelines	Commission Regulation (EU) No 141/2013 Eurostat (2013)	de jure/ de facto
		Primary	Input/Output	Guidelines for the questions about health, health status and chronic illness or condition, and access to health care in EU-SILC	Commission Regulation (EU) No 1983/2003	de jure/ de facto
	Routine/ administrative data	Secondary	Output	Definition of data items relating to mortality data (causes of death)	Commission Regulation (EU) No 328/2011	de jure
		Secondary	Output	Implementation of EU-wide morbidity statistics	Commission Regulation (EU) No 1338/2008	de jure
WHO	Health examination survey	Primary	Input	<i>Standardized protocol</i> for the risk factor surveillance. STEPwise approach to noncommunicable disease risk factor surveillance (STEPS)	World Health Organization (2016)	de facto/ voluntary
	Routine/ administrative data	Primary	Input	<i>Standardized protocol</i> for stroke surveillance. STEPwise approach to stroke surveillance.	World Health Organization (2006)	de facto/ voluntary
	Routine/ administrative data	Secondary	Output	Annual mortality data by age, sex and cause of death		

OECD	Routine/ administrative data	Secondary	Input/Output	Health data. <i>Definitions of indicators</i>	https://www.oecd.org/statistics/data-collection/health.htm	de facto/ voluntary
	Routine/ administrative data	Secondary	Input/Output	Health care quality indicators. <i>Definitions of indicators</i>	https://www.oecd.org/statistics/data-collection/health.htm	de facto/ voluntary
	Routine/ administrative data	Secondary	Input/Output	Health expenditure and financing. <i>Definitions of indicators</i>	https://www.oecd.org/statistics/data-collection/health.htm	de facto/ voluntary
European Network of Cancer Registers	Register data	Primary	Input/Output	Standardized definition of data items to be registers on cancer cases	Martos (2014)	
Joint OECD-Eurostat-WHO Data Collection	Routine/ administrative data	Secondary	Input/Output	Health Accounts (SHA)		
		Secondary	Input/Output	Non-Monetary Health Care Statistics		

B. Level of standardisation/harmonisation

In all previous projects which have collected health information some level of standardisation/harmonisation has been used. Nearly all projects which have obtained health information through primary data collection (mainly surveys) have developed standardised data collection protocols (input harmonisation). In projects using health information based on secondary use of already collected data output harmonisation protocols have been developed to obtain as comparable indicators as possible.

As long as standardisation/harmonisation procedures are not *de jure* binding, organisations using them can and also in many cases do make some changes to them. These deviations from standards may be due to practical reasons (cost and feasibility), or there is a wish to continue national/regional trends.

Different EU-level interview surveys (e.g. EU-SILC and EHIS) use different harmonisation approaches, i.e. different formulation of questions on same topic, which are laid down in the respective EU regulations dealing the implementation of the surveys (Commission Regulation (EU) No 1983/2003, Commission Regulation (EU) No 141/2013). Sometimes, a balance has to be found between elements of input and output harmonisation so as to take account of country-specific health monitoring requirements and national level comparability with previous surveys.

Further examples for feasibility can be found in data from health examination surveys, where it is recommended to conduct individual based sampling. In some countries such as the UK, it is difficult to obtain individual based sampling frames and samples and therefore household based surveys are commonly conducted. A similar situation often occurs with measurement devices, which may not be available at a reasonable price in some countries and alternative brands/types has to be used.

VI. Implications and limitations

Unless standardisation/harmonisation of collection of health information cannot be ensured, the comparability and reliability of obtained results is jeopardized.

Limitations for standardised/harmonized collection of health information are related to availability of data, data source and available resources. In an ideal case, primary data can be collected but quite often already collected data need to be used for secondary purposes.

In the questionnaire sent to the project leaders, the main obstacles seen for the standardised data collection were insufficient metadata, limited resources, absence of data in countries, use of different systems/ontologies for collection of primary data, data collection traditions and willingness to change them, and efforts to agree on harmonised protocols.

VII. Conclusions and recommendations

The importance of standardisation/harmonisation of collection of health information has been recognised among different projects and international organisations. Both standardised data collection protocols for the primary data collection and output harmonisation methods for secondary use of already collected data has been developed. Currently these protocols are published by projects as formal peer-review journal articles, web-publications or working documents, or in some cases kept confidential within a project. Protocols and recommendations for the international organisations are publicly available.

In different protocols and recommendations, occasionally the same topic areas are covered (Appendix 1). For example questions about smoking are included both to the EHIS and EHES protocol. It would be valuable to have one web site, a portal for health information, which lists existing protocols and recommendations and provides information about their possible differences.

In future, planned A European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy (HIREP-ERIC) should have a hub/node which is responsible for 1) development, maintenance and distribution of standardised protocols, both for input and output harmonisation, 2) providing training on proper use of these standards, 3) conducting evaluate the use of standards and 4) documentation of outcome of the standardisation and possible reasons for deviations.

When standardisation and harmonisation processes are well planned and documented, they can be executed already during the data collection and unnecessary delays in data cleaning and output delivery can be avoided. This will also ensure high quality data for research and evidence-based policy making.

VIII. References

Becker K, Seiwert M, Casteleyn L, et al. (2014) A systematic approach for designing a HBM pilot study for Europe. *Int J Hyg Environ Health*, 217(2-3): 312-322. doi:10.1016/j.ijheh.2013.07.004

Bernal-Delgado E, Christiansen T, Bloor K et al. (2015) ECHO: health care performance assessment in several European health systems. *Eur J Public Health* 2015; 25 Suppl 1: 3-7. doi: 10.1093/eurpub/cku219

Casteleyn L, Dumez B, Becker K et al. (2015) A pilot study on the feasibility of European harmonized human biomonitoring: Strategies towards a common approach, challenges and opportunities. *Environ Res*, 141: 3-14. doi:10.1016/j.envres.2014.10.028

Cano N, Aerts D et al. (2015) Communication in a Human biomonitoring study: Focus group work, public engagement and lessons learned in 17 European countries. *Environ Res*, 141: 31-41. doi:10.1016/j.envres.2014.12.003

Commission Regulation (EU) No 1983/2003 of 7 November 2003 implementing Regulation (EC) No 1177/2003 of the European Parliament and of the Council concerning Community statistics on income and living conditions (EU-SILC) as regards the list of target primary variables. Available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32003R1983&from=EN>

Commission Regulation (EU) No 328/2011 of 5 April 2011 implementing Regulation (EC) No 1338/2009 of the European Parliament and of the Council on Community statistics on public health and health and safety at work, as regards statistics on causes of death. Available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32011R0328&from=EN>

Commission Regulation (EU) No 141/2013 of 19 February 2013 implementing Regulation (EC) No 1338/2008 of the European Parliament and of the Council on Community statistics on public health and health and safety at work, as regards statistics based on the European Health Interview Survey (EHIS). Available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013R0141&from=EN>

Esteban M, Schindler BK, Jimenez JA et al. (2015) Mercury analysis in hair: Comparability and quality assessment within the transnational COPHES/DEMOCOPHES project. Environ Res, 141: 24-30. doi:10.1016/j.envres.2014.11.014

EuroHOPE (2012a) EuroHOPE Discussion Papers No 5. EuroHOPE AMI: Material, Methods and Indicators. Available at: http://www.eurohope.info/doc/EHDP5_AMI.pdf

EuroHOPE (2012b). EuroHOPE Discussion Papers No 8. EuroHOPE Breast Cancer: Material, Methods and Indicators. Available at: http://www.eurohope.info/doc/EHDP8_Breastcancer.pdf

EuroHOPE (2012c) EuroHOPE Discussion Paperes No 9. EuroHOPE VLBW: Material, Methods and Indicators. Available at: http://www.eurohope.info/doc/EHDP9_VLBWI.pdf

EuroHOPE (2013) EuroHOPE Discussion Papers No 6. EuroHOPE Stroke: Material, Methods and Indicators. Available at: http://www.eurohope.info/doc/EHDP6_Stroke.pdf

Euro-Persistat (2012) Euro-Persistat list of indicator, updated 2012. Available at: <http://www.europeristat.com/images/doc/updated%20indicator%20list.pdf>10. Exley K,

EuroSafe (2014). IDB-JAMIE Full data set (IDB-FDS) Data Dictionary. Available at: <http://www.eurosafe.eu.com/uploads/inline-files/IDB%20JAMIE%20FDS%20Data%20Dictionary%20MAR14.pdf>

Eurostat (2013). European Health Interview Survey (EHIS wave 2). Methodological manual. European Union. Available at: <http://ec.europa.eu/eurostat/documents/3859598/5926729/KS-RA-13-018-EN.PDF/26c7ea80-01d8-420e-bdc6-e9d5f6578e7c>

Eurostat (2016). EU labour force survey - development and history. Output harmonisation approach. Available at: http://ec.europa.eu/eurostat/statistics-explained/index.php/EU_labour_force_survey_%E2%80%93_development_and_history#Output_harmonisation_approach

- Fiddicke U, Becker K, Schwedler G et al. (2015). Lessons learnt on recruitment and fieldwork from a pilot European human biomonitoring survey. *Environ Res*, 141: 15-23. doi:10.1016/j.envres.2014.08.039
- Giampaoli S, Hammar N, Adany R et al. Population-based register of stroke: manual of operations. *Eur J Card Prev and Rehabil* 2007; 14 (Suppl 3): S23-S41
- Madsen M, Gudnason V, Pajak A, Palmieri L et al. (2007) Population-based register of acute myocardial infarction: manual of operations. *Eur J Card Prev and Rehabil* 2007; 14 (Suppl 3): S3-S22
- Martos C, Crocetti E, Visser I et al. (2014) A proposal on cancer data quality checks: one common procedure for European cancer registries. Joint Research Centre. doi:10.2788/182378
- OECD (2011) Perceived health status in Health at a Glance 2011. OECD Indicators. OECD Publishing. Available at: http://dx.doi.org/10.1787/health_glance-2011-12-en
- Primatesta P, Allender S, Ciccarelli P et al. (2007) Cardiovascular surveys: manual of operations. *Eur J Card Prev and Rehabil* 2007; 14 (Suppl 3): S43-S61
- Roland G (2003), p.4 Working Paper 19 - The change from Input Harmonisation to Ex-post Harmonisation in national Samples of the European Community Household Panel - Implication on Data Quality, Wiesbaden, Statistisches Bundesamt
- Saarela O, Kulathinal S for the MORGAM Project (2011). Description and quality of baseline data: Awareness and treatment of high blood pressure and cholesterol. Available at: http://www.thl.fi/publications/morgam/ga/baseline/highbpchol/highbpcholga.htm#Have_you_ever_been_told_by_a_doctor_or_other_health_worker_that_you_have_high_blood_p_ressure
- Schindler BK, Esteban M, Koch HM et al. (2014) The European COPHES/DEMOCOPHES project: towards transnational comparability and reliability of human biomonitoring results. *Int J Hyg Environ Health*, 2017(6): 653-661. doi:10.1016/j.ijheh.2013.12.002
- Survey Research Centre (2011) Guidelines for best practice in cross-cultural surveys. ISBN 978-0-9828418-1-5 (Available at <http://ccsg.isr.umich.edu/pdf/FullGuidelines1301.pdf>)
- Tolonen H (ed.) (2013a) EHES Manual, Part A. Planning and preparation of the survey. National Institute for Health and Welfare. Directions 2013_001. URN:ISBN:978-952-245-842-1, URL: <http://url.fi/URN:ISBN:978-952-245-842-1>
- Tolonen H (ed.) (2013b) EHES Manual, Part B. Fieldwork procedures. National Institute for Health and Welfare. Directions 2013_002. URN:ISBN:978-952-245-843-8, URL: <http://urn.fi/URN:ISBN:978-952-245-843-8>
- Tolonen H (ed.) (2013c) EHES Manual, Part C. European level collaboration. National Institute for Health and Welfare. Directions 2013_003. URN:ISBN:978-952-245-846-9, URL: <http://urn.fi/URN:ISBN:978-952-245-846-9>

Tolonen H (ed.) (2016a) EHES Manual, Part A. Planning and preparation of the survey. 2nd edition. National Institute for Health and Welfare. Directions 2016_13. URN:ISBN:978-952-302-700-8, URL: <http://urn.fi/URN:ISBN:978-952-302-700-8>

Tolonen H (ed.) (2013b) EHES Manual, Part B. Fieldwork procedures. 2nd edition. National Institute for Health and Welfare. Directions 2016_14. URN:ISBN:978-952-302-701-5, URL: <http://urn.fi/URN:ISBN:978-952-302-701-5>

Tolonen H (ed.) (2013c) EHES Manual, Part C. European level collaboration. 2nd edition. National Institute for Health and Welfare. Directions 2016_15. URN:ISBN:978-952-302-702-2, URL: <http://urn.fi/URN:ISBN:978-952-302-702-2>

Tolonen H, Ferrario M & Kuulasmaa K. (2005) Standardization of total cholesterol measurement in population surveys - pre-analytic sources of variation and their effect on the prevalence of hypercholesterolaemia. *Eur J Card Prev and Rehab*, 12: 257-267

Tolonen H, Koponen P, Naska A et al. (2015) Challenges in standardization of blood pressure measurement at the population level. *BMC Medical Research Methodology*, 15:33. doi:10.1186/s12874-015-0020-3

United Nations Department of Economic and Social Affairs, Statistics Division (2000) Handbook on Geographic Information Systems and Digital Mapping, Studies in Methods, Series F, No. 79, , New York, Annex VI - Glossary

Verschuuren M, Gissler M, Kilpelainen K, Tuomi-Nikula A, Sihvonen AP, et al. Public health indicators for the EU: the joint action for ECHIM (European Community Health Indicators & Monitoring). *Arch Public Health* 2013; 71(1):12. doi: 10.1186/0778-7367-71-12

World Health Organization (2006). WHO STEPS Stroke Manual: The WHO STEPwise approach to stroke surveillance. Geneva, World Health Organization. Available at: <http://www.who.int/chp/steps/Manual.pdf?ua=1>

World Health Organization (2016). STEPS Manual. Available at: <http://www.who.int/chp/steps/manual/en/>

IX. Appendix 1. Examples of topic areas covered by existing standardised/harmonised procedures

Population surveys - standardisation of primary data collection

Topic	Project/International organisation/International standard	
Survey organisation	Target population, sampling including sampling frame(s), sample size and sampling procedure	EHIS, EHES, EFSA-EU Menu
	Recruitment of invitees	EHES, COPHES/DEMOCOPHES, EFSA-EU Menu
	Legal and ethical issues including informed consent	EHES, EFSA-EU Menu
	Internal and external quality control	EHES, COPHES/DEMOCOPHES, EFSA-EU Menu
	Questionnaire administration mode	EHIS, EU-SILC, EFSA-EU Menu
Questionnaire items/modules	Socio-demographic background	EHIS, EHES, EU-SILC, EUROCISS, WHO-STEPS
	Self-perceived health	EHIS, EHES, EU-SILC
	Long-standing health problems	EHIS, EHES, EU-SILC
	Activity limitation	EHIS, EHES, EU-SILC, International standards (ADL/IADL, MEHM)
	Diseases and chronic conditions	EHIS, EHES, EUROCISS, WHO-STEPS
	Accidents and injuries	EHIS
	Asthma and allergies	ENRIECO/OBELIX (ISAAC questionnaire)
	Absence from work due to health problems	EHIS
	Physical and sensory functional limitations (problems seeing/hearing/walking)	EHIS
	Personal care activities	EHIS
	Household activities	EHIS
	Pain	EHIS
	Mental health	EHIS: Patient Health Questionnaire (PHQ-8), International standards (WHO-WMH-CIDI, MFQ, SMFQ, MDQ, WEMWBS, HMI-5)
	Use of inpatient and day care	EHIS, EU-SILC
	Use of ambulatory and home care	EHIS
	Medicine use	EHIS, EHES, EUROCISS, WHO-STEPS
	Preventive services	EHIS, EHES, EUROCISS, WHO-STEPS

	Unmet needs for health care	EHIS, EU-SILC
	Weight and height	EHIS, EHES, EFSA-EU Menu
	Physical activity	EHIS, EU-SILC, International standards (IPAQ, GPAQ and RPAQ), WHO-STEPS
	Consumption of fruit and vegetables	EHIS, EU-SILC, EFSA-EU Menu, WHO-STEPS
	Smoking	EHIS, EHES, WHO-STEPS
	Alcohol consumption	EHIS, WHO-STEPS
	Social support	EHIS
	Provision of informal care or assistance	EHIS
	Quality of life	International standards (WHOQOL, McGill GOL, SF-36)
Physical examinations	Height	EHES, EUROCISS, WHO-STEPS
	Weight	EHES, EUROCISS, WHO-STEPS
	Waist circumference	EHES, EUROCISS, WHO-STEPS
	Hip circumference	EHES, WHO-STEPS
	Blood pressure	EHES, EUROCISS, WHO-STEPS
	Physical function tests	EHES, FEHES
	Cognitive function tests	
	Electrocardiogram	EUROCISS
	Ankle-brachial index	EUROCISS, FEHES
	Ultrasound of peripheral arteries	EUROCISS
Collection of biological samples	Blood sample for lipids	EHES, EUROCISS, WHO-STEPS
	Blood samples for glucose/HbA _{1c}	EHES, WHO-STEPS
	Blood samples for other analysis	
	Urine	COPHES/DEMOCOPHES (spot) EHES (spot/24 h)
	Hair	COPHES/DEMOCOPHES