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Measuring health literacy in Europe: Introducing the European Health Literacy Survey Questionnaire (HLS-EU-Q)

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Introduction

At the beginning of the millennium, the growing interest and concerns regarding the impact of limited health literacy in North America was recognised, and health literacy was brought up among European politicians and researchers as being of relevance for active health citizenship and patient participation in contrast to the more prevailing paternalistic views. However, no European population data on health literacy existed, and it became evident that more information was needed to inform the policy discussions (Sørensen and Brand, 2017). Compared to the US, Canada and Australia, measuring health literacy not only came to Europe rather late, but measurement also followed quite a different approach. While in the US, after few studies in the tradition of population literacy measurement – using, for example, the Health and Literacy Scale (HALS) – the bulk of health literacy studies focused on the consequences of the low clinical health literacy of patient populations, using for measurement (rather short) instruments of functional health literacy (Rudd, 2017), in Europe, measurement started with a rather broad concept of health literacy in general populations (Sørensen et al, 2012; Wang et al, 2012; Pelikan and Ganahl, 2017a, b).

Crucial for the European developments were Ilona Kickbusch (Kickbusch, 2001, 2002; Kickbusch et al, 2006; Kickbusch and Maag, 2008) and Don Nutbeam (Nutbeam, 2000; Nutbeam and Kickbusch, 2000), who had recognised the potential of health literacy for health promotion and public health, besides its importance for healthcare (see Chapter 2, this volume). From 2004 onwards, Ilona Kickbusch advocated for health literacy within the European Health Forum Gastein (Kickbusch, 2004), and initiated the HLS-CH study in Switzerland in 2006 (Wang et al, 2012). At the European Public Health Conference (EUPHA) in Montreux in 2006, a representative from the European Commission was

convinced of the relevance of health literacy for the European health agenda, and a group was initiated by Ilona Kickbusch, Jürgen Pelikan and Helmut Brandt to form a consortium, develop a proposal and ensure funding for a European health literacy study.

This chapter introduces the European Health Literacy Survey Questionnaire (HLS-EU-Q), and discusses its impact for health literacy policy, research and practice. From a life course perspective, the HLS-EU study included participants aged 15+, hence the survey results regard youth, adulthood and ageing, but not childhood.

The HLS-EU study

The HLS-EU was supported by the Executive Agency for Health and Consumers (EAHC) of the European Union (EU). The project had five objectives:

- Adapt a model instrument for measuring health literacy in Europe.
- Generate first-time data on health literacy in European countries, providing indicators for national and EU monitoring.
- Make comparative assessment of health literacy in European countries.
- Create National Advisory Bodies in countries participating in the survey and document different valorisation strategies following national structures and priorities.
- Establish a European Health Literacy Network.

The HLS-EU Consortium, including academic institutions from Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain conducted the project.

The HLS-EU concept and definition of health literacy

To explore and define health literacy, a literature review was undertaken. The review identified 17 definitions and 12 models from which a content analysis yielded a comprehensive, 'all-inclusive' consensus definition and conceptual model (Sørensen et al, 2012; see Chapter 1). The resulting conceptual model and definition adequately mirror the evolution of the broadening understanding of health literacy in research, practice and policy within the last two decades (Pelikan and Ganahl, 2017a, b). According to the HLS-EU Consortium,

> Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al, 2012, p 3)

The definition and conceptual model covers the continuum of health when being ill, at risk and healthy from a personal view and from a systemic view in terms of healthcare, disease prevention and health promotion. It covers various aspects of health literacy (Nutbeam, 2008) in the modern 'health society' (Kickbusch, 2007), including clinical (Pleasant and Kuruvilla, 2008), medical (Peerson and Saunders, 2009), patient (Ishikawa and Yano, 2008), and public health aspects (Freedman et al, 2009) of health literacy. The definition relates not only to reactively understanding information offered by experts, but also to proactively finding/accessing, evaluating/appraising and personally using/applying information, that is, to the comprehensive competencies of information management necessary in the modern 'information society', 'knowledge society' or 'multi-option society'. The four steps of information management addressed in the definition and model adequately fulfil in an analytical fashion what Nutbeam (2008, p 2076) demanded for health literacy measures,

> to include assessment of a person's ability to
> - gain access to age and context specific information from a variety of different sources,
> - discriminate between sources of information,
> - understand and personalise health information that has been obtained,
> - appropriately apply relevant health information for personal benefit.

In addition, it relates to the typology of functional, interactive and critical health literacy (Nutbeam, 2000), where functional health literacy refers to understanding, interactive health literacy to finding/accessing and critical health literacy to evaluating/appraising information to form decisions for maintaining and improving health and quality of life. Health literacy is not seen just as knowledge, which has a very short half-time in late modernity, and cognitive skills, but also as an emotional resource for motivating health-relevant action. Thus, health literacy is not narrowly understood as relevant for adequately fulfilling a compliant or adherent patient's role in healthcare, but as a resource for enacting in a healthy way in all roles in all settings and systems in everyday life in late modern society. It reflects the World Health Organization's (WHO) Ottawa Charter for health promotion: 'Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love' (WHO, 1986). Although, the HLS-EU definition only implicitly relates to the interactive, dual relational character of health literacy, as the fit of personal competencies to the complexity of situational demands (Parker, 2009; Brach et al, 2012; Kickbusch et al, 2013; Pelikan and Ganahl, 2017a, b), when stating the competencies related to accessing, understanding, appraising and applying information concerning healthcare, disease prevention and health promotion, the operationalisation of the definition into an instrument for measuring health literacy takes the dual aspect more explicitly into account by measuring difficulties of people for different tasks. For more

clarifying details, see Pelikan et al (2013; see also Pelikan and Ganahl, 2017a, b). For analysing data, a generic model (see Figure 8.1) has been used (HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b), which distinguishes between health literacy and its personal and situational determinants and its personal consequences for health behaviours, health status and illness behaviours. The model assumes one dominant direction of causality of consequences, but also allows for cyclical causal links in the other direction.

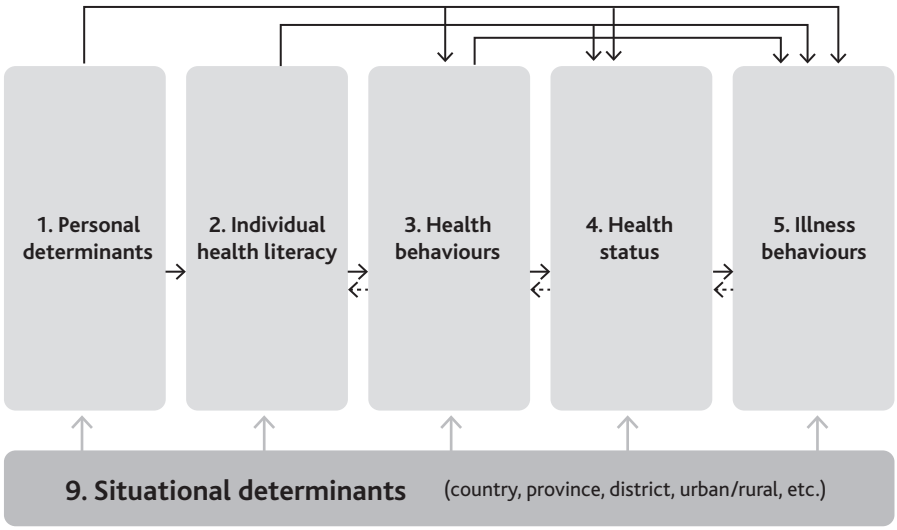
The HLS-EU survey questionnaire

Operationalising health literacy

The questionnaire development (item generation, focus groups, field test/pre-testing, expert consultation, finalisation of the questionnaire, plain language check, translation) is described in detail in Sørensen et al (2013). Here, we highlight the most important strategic decisions taken for operationalising the HLS-EU definition and conceptual model into the final form of the HLS-EU-Q.

The instrument had to be comprehensive, not only in relation to content, but also concerning different kinds of competencies involved. A literature review proved that the existing tools did not cover the HLS-EU definition and conceptual model as they were too specific and were not useful for a population study. Furthermore, for compatibility with the interview-based Eurobarometer approach, it was decided to construct a 'subjective' 'perception-based' in contrast to an 'objective' 'performance-based' (Schulz and Hartung, 2017) instrument.

Figure 8.1: Generic Vienna model of health literacy defining the principal determinants and consequences of health literacy



Source: Pelikan and Ganahl (2017a, b)

The HLS-EU instrument reflects two traditions of measuring health literacy – the example of the HALS (Rudd et al, 2004), where partly complex and concrete tasks of health-relevant decisions or actions of everyday life were tested, and asking about the self-perceived difficulty of a specific task (Chew et al, 2004, 2008).

To operationalise the definition and conceptual model a matrix was constructed focusing on the three overall domains of health and four cognitive information-processing competencies (Table 8.1). For each of the 12 sub-domains relevant concrete tasks were identified. Hence, this 3×4 matrix represents the concept of comprehensive health literacy by 12 different components, each combining one of the three domains of healthcare, disease prevention and health promotion with one of the four stages of information management, that is, finding, understanding, appraising and using information. By this analytical decomposition and a standardised format of items, it is possible to have not just one measure for

Table 8.1: HLS-EU health literacy matrix

(47 items)	**Access/ find/obtain information relevant to health** *(13 items)*	**Understand information relevant to health** *(11 items)*	**Appraise/ judge/evaluate information relevant to health** *(12 items)*	**Apply/use information relevant to health** *(11 items)*
Healthcare *(16 items)*	Ability to access information on medical and clinical issues *(4 items)*	Ability to understand medical information and derive meaning *(4 items)*	Ability to interpret and evaluate medical information *(4 items)*	Ability to make informed decisions on medical issues *(4 items)*
Disease prevention *(15 items)*	Ability to access information on risk factors for health *(4 items)*	Ability to understand information on risk factors and derive meaning *(3 items)*	Ability to interpret and evaluate information on risk factors for health *(5 items)*	Ability to make informed decisions on risk factors for health *(3 items)*
Health promotion *(16 items)*	Ability to update oneself on determinants of health in the social and physical environment *(5 items)*	Ability to understand information on determinants of health in the social and physical environment and derive meaning *(4 items)*	Ability to interpret and evaluate information on health determinants in the social and physical environment *(3 items)*	Ability to make informed decisions on health determinants in the social and physical environment *(4 items)*

Note: Number of items in the HLS-EU-Q47 for each cell was added into the original table of Sørensen et al (2012) for this publication.

Source: Sørensen et al (2012)

comprehensive health literacy, but also additional measures for specific sub- or sub-sub dimensions.

The Consortium opted for questions (instead of rhetorical statements), since questions in an interview can be more easily and directly answered than statements, especially by less educated people.

As an underlying dimension for judging the concrete tasks, experienced difficulty of performing the task was chosen. Thus, one gets information of differences in difficulty of various tasks in one population, and by counting the number of items experienced as difficult by one individual, a measure for his/her relative health literacy. Furthermore, all items are comparable with each other and can be aggregated to different kinds of indices and one general measure, which does not hold true for some other comparable health literacy instruments (Chew et al, 2004; Wang et al, 2012; Osborne et al, 2013).

For answering the questions, a Likert scale of four symmetrical answer categories was chosen. Four categories allow for differentiation and can still be handled easily in an interview, and the symmetrical even number avoids a nebulous middle category. Also, an even number of categories can be meaningfully dichotomised in later statistical analysis of data, if preferred or necessary. ('Don't know' was not offered as an answer category, but spontaneous 'don't know' answers were coded as 'no answer' by the interviewer.)

The four categories offered were ordered from 'very easy', 'fairly easy', 'fairly difficult' to 'very difficult' to avoid a response set overstating assessed difficulty of items. Thus, the complete formulation of an exemplary item was: 'On a scale from "very easy" to "very difficult", how easy would you say it is to understand what your doctor says to you?' 'Very easy' – 'fairly easy' – 'fairly difficult' – 'very difficult' (no answer).

To also guarantee a certain degree of reliability for sub-sub-indices, it was planned to have 3-5 indicators for each cell of the health literacy matrix (see Table 8.1). Concrete items were either chosen from existing examples in the literature or newly drafted by a Delphi procedure among Consortium members or by expert consultation (see Sørensen et al, 2013), yielding a total of 47 items. A list of all items can be found in HLS-EU Consortium (2012) and in Sørensen et al (2013).

In summary, by its specific format the HLS-EU-Q47 fulfils different functions for policy, practice and research very well. By measuring 47 concrete tasks concerning their relative difficulty in handling for specific populations or sub-populations, it offers a solid diagnostic basis for health policy to plan concrete interventions for improving specific aspects of health literacy for these populations. By measuring these tasks in a theory-based and standardised format, answers can also be aggregated to different kinds of (sub-)indices, which can more easily and economically be used in correlation and regression analyses to research the associations of health literacy to other variables, especially to the determinants and consequences of health literacy. Furthermore, the standardised tasks-oriented procedure also allows for developing comparable further sets of items and indices

for tasks relevant for specific sub-populations, as has been already done for migrants (Ganahl et al, 2016, 2017), for adolescents (Domanska et al, 2016) or for children (Okan and Bollweg, 2018).

Selecting and operationalising the specific determinants and consequences of health literacy

Besides the 47 items for measuring health literacy, the original HLS-EU-Q (HLS-EU-Q86) contained 39 variables, operationalising factors of the HLS-EU conceptual model into measurable indicators. Where it was possible, validated standard indicators have been selected. The personal determinants of health literacy included the indicators gender, age, education, self-reported social status, indicators for financial situation (including kind of health insurance), main status of employment (including in a healthcare profession), migration status, nationality, family/household situation (for example, legal marital status, children, household living situation) and the Newest Vital Sign (NVS) test for functional health literacy (Weiss et al, 2005). The situational determinants included country, region, postal code and size of locality. Indicators concerning health risks/health behaviours included smoking, alcohol consumption, physical activity and BMI (body mass index). Health status was measured by the three questions of the Minimum European Health Module (MEHM), and illness behaviour by questions on frequency of use of professional healthcare services (emergency services, doctor's visits, hospital and other health professionals). These variables aimed at testing the validity of the HLS-EU-Q47 and for comparing associations of health literacy with possible determinants and consequences between the surveyed countries.

Data collection and data management in the HLS-EU study

Data was collected by computer-assisted personal interviewing (CAPI) or paper-assisted personal interviewing (PAPI). Interviewing for the HLS-EU-Q47 part took on average 10 minutes, and 25 minutes for the total HLS-EU-Q86. The HLS-EU study was based on multistage random samples of about 1,000 EU-citizens aged 15 (for more details, see HLS-EU Consortium, 2012). Meanwhile, the instrument has been used in a self-administered way (Duong et al, 2017), online on the internet (Nakayama et al, 2015), and through telephone interviews (Ganahl et al, 2016, 2017; Finbråten et al, 2018).

The response rates varied by country – from 36 per cent in the Netherlands to more than 70 per cent in Bulgaria. A somewhat differing recruitment process can probably explain the considerable low response rate in the Netherlands. National samples were weighted by gender, age group and size of locality based on national census data to increase representativeness.

Since the eight participating countries are not representative of the EU, no values for the 'average European citizen' could be calculated. Instead, the total

sample was used to have an average benchmark for the participating countries, but without a weighting for country size.

Main results (and publications)

Results of the original HLS-EU study have been published and widely presented. Publications compare the eight countries (HLS-EU Consortium, 2012; Sørensen et al, 2015) or are presented for single countries, for example, Ireland (Doyle et al, 2012), the Netherlands (van der Heide et al, 2015), Poland (Słońska et al, 2015) or for an extended sample of Austria (Pelikan et al, 2013).

Data analysis

The format of the HLS-EU-Q47 allows for two kinds of analysis, one for single items and one for aggregated indices. No answer rates for single items were low, with one exception (see HLS-EU Consortium, 2012, table 3). Items have been compared in relation to their difficulty either by using the full four-category distribution or a reduced dichotomous categorisation (combined 'easy' and 'fairly easy' vs 'fairly difficult' and 'difficult'). The difficulty of the 47 items varied considerably by content and also for many items by country (see HLS-EU Consortium, 2012, table 4, figures 4-6), which suggests an acceptable sensitivity of the instrument. Furthermore, all items were positively and partly significantly correlated with each other.

While the results for the concrete single items are relevant for diagnosing problems and deficits concerning specific aspects of health literacy in a country or region for planning tailored interventions and measures to improve health literacy by health policy, aggregate health literacy measures are more convenient and economical for describing levels and associations of health literacy and for benchmarking these.

Indices were constructed for people answering at least 80 per cent of the items underlying a specific index by adding values for answer categories (very easy = 4, rather easy = 3, rather difficult = 2, very difficult = 1). Thus, larger index values suggest higher health literacy. For ease of comparability, the general index and the seven sub-indices were standardised into a scale from 0 to 50 (index = (mean–1)*(50/3)) and the sub-sub-indices into one from 0 to 5.

Cronbach's alpha for the general index and for sub-indices was considerably above 0.7, and for sub-sub-indices, at least near to 0.7 (Pelikan et al, 2014, slide 23). For the general index and the sub-indices a normal distribution with some ceiling effects for higher health literacy was found (Pelikan et al, 2014, slides 24-26), indicating that the indices are more sensitive for lower than for higher health literacy scores.

Mean values and standard deviations of indices differed considerably by country (HLS-EU Consortium, 2012). There was also variation by sub-indices, with lower mean values for health literacy related to health promotion or disease

prevention compared to healthcare respectively for appreciation or accessing of information compared to understanding or applying information (Pelikan and Ganahl, 2017a, b, slides 24-26; Pelikan et al, 2014).

Pearson correlations between indices are rather high – for the general index with the seven sub-indices around $r = 0.90$, for the sub-indices among each other between $r = 0.70$ and $r = 0.80$, for the sub-sub-indices with the general index also between $r = 0.70$ and $r = 0.80$, respectively, with the sub-indices between $r = 0.54$ and $r = 0.84$, and among each other between $r = 0.42$ and $r = 0.69$ (Pelikan and Ganahl, 2017a, b). These correlations suggest that the items of the HLS-EU-Q47 are measuring some common health literacy quality, but also that sub- and sub-sub-indices are measuring differing specific aspects of health literacy.

In comparison, the correlations with the NVS were considerably lower, depending on index, between $r = 0.18$ and $r = 0.29$ (Pelikan and Ganahl, 2017a, b), which is in the same order of strength of correlation as with education as a determinant of health literacy.

As for other health literacy measures, health literacy levels have been defined for the HLS-EU-Q47 to allow for comparing percentages of levels that are intuitively more easy to interpret than means or standard deviations of the indices. Four levels of health literacy have been defined: inadequate health literacy (0-25 pts or 50%), problematic health literacy (>25-33 pts or 66%), sufficient health literacy (>33-42 pts or 80%) and excellent health literacy (>42-50 pts or top 20%). For some analyses, the levels of 'inadequate' and 'problematic' were combined to 'limited' health literacy (HLS-EU Consortium, 2012, pp 28-30; Sørensen et al, 2015).

The results show that nearly every second citizen in the total sample had limited health literacy. However, the percentage of limited health literacy varied considerably by country – between 29 per cent for the Netherlands and 62 per cent for Bulgaria. The percentage can be up to 75 per cent for certain vulnerable or disadvantaged groups, for example, people with low education or with financial difficulties, low self-assessed social status, senior citizens, as well as with low self-assessed health (for more details, see HLS-EU Consortium, 2012; Sørensen et al, 2015; Pelikan and Ganahl, 2017a, b).

Analysis of associations of health literacy with determinants and consequences of health literacy

Measured by the HLS-EU-Q47 a relevant social gradient for health literacy has been demonstrated in regression models including gender, age, education, self-assessed social status and financial deprivation in the original HLS-EU study and in follow-up studies. However, the amount of variance explained and the relative importance of the five social determinants differ considerably by country (HLS-EU Consortium, 2012; Sørensen et al, 2015; Pelikan and Ganahl, 2017a, b).

The health literacy results related to health behaviours or health risks show a consistent association with frequency of physical activity and partly with

BMI, but are inconclusive for alcohol consumption and smoking (see HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b). Health literacy is a consistent, significant and remarkable predictor in bi-variate and multi-variate models for indicators of self-assessed health status (see HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b). Finally, there are significant associations of health literacy with usage of health services (see HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b).

Development of short forms of the HLS-EU-Q47

For measuring comprehensive health literacy, the HLS-EU-Q47 is an efficient instrument compared to performance-based comprehensive tests, such as the HALS. However, it is seen as too long for screening purposes. Therefore, short forms have been developed. Two kinds of strategies have been followed with a different approach in Europe and in Asia. A team of the European Consortium using the HLS-EU data developed the HLS-EU-Q16 and HLS-EU-Q6 based on Item Response Theory and Rasch Analysis (for more details, see Pelikan et al, 2014; Pelikan and Ganahl, 2017a, b). Thus, for the short forms, primarily psychometric properties of a one-dimensional scale and representation of the underlying scope and theoretical concept of the long form as far as possible was intended.

For selecting items, a one-parametric dichotomous Rasch model was used, with items dichotomised into two categories, 'easy' ('fairly' or 'very' easy = 1) and 'difficult' ('fairly' and 'very' difficult = 0). Analyses were operationalised for every country and for the total sample, with three split criteria: median, gender and dichotomised level of education within each country. A sub-set of the same 16 items satisfied Rasch characteristics for each of the eight countries, but the item order occasionally varied. In further studies, the Rasch homogeneity of the 16 items was confirmed, for example, for Austrian adolescents (Röthlin et al, 2013) and migrant populations in Austria (Ganahl et al, 2016), as well as in studies of general populations, for example, for the Czech Republic and for Hungary (Koltai and Kun, 2016; Kučera et al, 2016). The HLS-EU matrix is represented by the 16 items except for the cell 'applying information' for 'health promotion', where none of the original items fulfilled the Rasch criteria.

Scale values are calculated as simple sum scores only for respondents who answered at least 14 items, and varied between 0 and 16. Three levels were defined for health literacy: short-scale, inadequate (scale values = 0-8), problematic (9-12) and adequate (13-16). Score values for the sub-scales of the short form can also be calculated, but levels for these have not been defined.

Correlations with the index of the long form were very high – $r = 0.82$ for the total sample – and varied for the countries between $r = 0.73$ and $r = 0.88$. Correlations with functional health literacy (NVS test) were similar to these of the index of the long form ($r = 0.25$ for total), varying between $r = 0.14$ and $r = 0.38$ for the countries. Also, correlation patterns with important determinants

and consequences of health literacy were very similar for the short and long form of the instrument. When the short form is calculated using the four categories as for the long form, even better results concerning correlations between the two forms can be achieved.

Applying the HLS-EU-Q16 short form takes about 3 minutes on average. An even shorter version, called the 'short short form', the HLS-EU-Q6, containing 6 of the 16 items, which takes about a minute of interviewing time, was also constructed and validated (for details, see Pelikan et al, 2014). Using data from a survey in Taiwan (Duong et al, 2015) and Principal Component Analysis, a team developed a short form of 12 items, one for each of the 12 cells of the HLS-EU matrix (HL-SF12) (Duong et al, 2017). A team in Norway established another short version of the European Health Literacy Survey Questionnaire – the HLS-Q12 – by using latent trait analyses applying Rasch modelling and confirmatory factor analysis (Finbråten et al, 2018).

Wider application of the HLS-EU-Q in research

Follow-up studies

In the original HLS-EU survey only eight EU member states were included, due to financial limitations of funding from the European Commission. However, the consolidation and advocacy through Health Literacy Europe, the network and national advisory groups that were established with the project, motivated a number of further countries to execute similar surveys using the HLS-EU methodology and instrument. To date, the HLS-EU survey has been conducted in Austria, Belgium, Czech Republic, Denmark, Germany, Hungary, Italy, Malta, Portugal and Switzerland in Europe and in Asian countries such as Indonesia, Israel, Japan, Kazakhstan, Malaysia, Myanmar, Taiwan and Vietnam. Table 8.2 gives an overview of these surveys with a description of their characteristics. Furthermore, the HLS-EU-Q47/Q16 or Q6 has been used in a number of specific studies in different countries (see Pelikan and Ganahl, 2017a, b), which is out of the scope for this chapter.

Wider application in policy

The European Office of the WHO recognises the impact of the HLS-EU study in its publication *Health literacy: The solid facts* (Kickbusch et al, 2013), which is available in English, German (2016), Mandarin (2016) and Russian (2014), and presents the HLS-EU definition, conceptual model, the matrix and the results of the HLS-EU survey. The results of the HLS-EU have initiated public debate on health literacy and stimulated political action to take specific measures for improving health literacy in countries worldwide. The European Health Literacy Consortium received the European Health Award in 2012 for its societal impact on health policy.

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Europe				
HLS-EU	Summer 2011	European Commission and national funds	University of Maastricht (coordination)	Cross-sectional, observational, CAPI, random route sampling method – multi-stage sampling, Eurobarometer standards
HLS-Austria			Ludwig Boltzmann Institute, Health Promotion Research	
HLS-Bulgaria			Medical University Sofia	
HLS-Greece			National School of Public Health, Greece	
HLS-North Rhine-Westphalia			Landesinstitut für Gesundheit und Arbeit, Nordrhein-Westfalen	
HLS-Ireland			University College Dublin	
HLS-Netherlands			National Institute of Public Health and the Environment, the Netherlands	
HLS-Poland			Instytut Kardiologii	
HLS-Spain			University of Murcia	
HLS-AT (Austria)	November 2011	European Commission, Austrian Health Promotion Fund, Scientific Grant Merck, Sharp & Dohme	Ludwig Boltzmann Institute, Health Promotion Research	See design used in HLS-EU
HLS-Kosovo	2011	United Nations Population Fund (UNFPA)	Department of International Health, School for Public Health and Primary Care (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands University of Medicine, Tirana, Albania	Stratified, simple random sample, structured interview-administered questionnaire
HLS-Albania	September 2012-February 2014	University of Medicine, Tirana, Albania	Department of International Health, School for Public Health and Primary Care (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands University of Medicine, Tirana, Albania	Population-based simple random sample within three health centres and one polyclinic, face-to-face interviews

	Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
		>15 years	8,102	HLS-EU-Q47	HLS-EU Consortium (2012); Sørensen et al (2015); Pelikan et al (2017a, b)
	Austria		1,015		
	Bulgaria		1,002		
	Greece (Athens region)		1,057		Doyle et al (2012)
	Germany (North Rhine-Westphalia)		1,000		
	Ireland		1,000		
	The Netherlands		1,005		van der Heide et al (2013)
	Poland		1,023		Słońska et al (2015)
	Spain		1,000		
	Extended Austrian HLS-EU sample in order to better reflect the nine Austrian federal states	>15 years	1,813	HLS-EU-Q47	Pelikan et al (2013)
	Kosovo	≥65 years	1,753	HLS-EU-Q47	Toçi et al (2013)
	Tirana municipality	≥18 years	1,152	HLS-EU-Q47	Toçi et al (2014)

(continued)

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire (continued)

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Europe (continued)				
HLS-Denmark[a]	January-April 2013	Supported by the pharmaceutical company MSD Denmark	Department of Public Health, Section for Health Promotion and Health Services, Aarhus University, Aarhus, Denmark	Self-administered paper or web-based questionnaire, random sample derived from the Danish Civil Registration System among citizens in the Central Denmark Regions
HLS-Germany	October 2013-June 2014	German Federal Ministry of Health	Robert Koch Institute	Internet and self-administered paper within the German Health Update Survey (GEDA)
HLS-Belgium	Spring 2014	No information was found	Université Catholique de Louvain + Mutualité Chrétienne/Christelijke Mutualiteit	Internet survey
HLS-Portugal	June-August 2014	No information was found	ISCTE – Instituto Universitário de Lisboa	Random route methodology for selection of dwelling, quota method for selection of interviewee
HLS-Malta	July 2014	Office of the Commissioner for Mental Health within the Ministry for Energy and Health	National Statistics Office, Malta	CATI, stratified random sample
HLS-GER (Germany)	July and August 2014	German Federal Ministry for Justice and Consumer Protection	University of Bielefeld	CAPI, multi-stage random sample
HLS-Czech Republic	January 2015	Czech Ministry of Health and the Country Office of WHO in the Czech Republic	National Institute of Public Health	See HLS-EU methodology
HLS-Hungary	May-June 2015	Association of Innovative Pharmaceutical Manufacturers	Szinapszis Market Research and Consulting Ltd	See HLS-EU methodology

	Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
	Denmark	>25 years	29,473	HLS-EU-Q16	
	Germany	≥18 years	2,222 online, 2,730 self-administered paper	HLS-EU-Q16	Jordan et al (2015)
	Belgium	≥18 years	9,617	HLS-EU-Q16	Vandenbosch et al (2016)
	Portugal	≥15 years	2,104	HLS-EU-Q47	Espanha and Ávila (2016)
	Malta	≥18 years	1,514	EU-HLS 16 (same items as in the HLS-EU-Q16 but different index calculations)	Office of the Commissioner for Mental Health (2014)
	Germany	>15 years	2,000	HLS-EU-Q47	Berens et al (2016); Schaeffer et al (2016, 2017a, b); Vogt et al (2017)
	Czech Republic	>15 years	1,037	HLS-EU-Q47	Kučera et al (2016)
	Hungary	>16 years	1,008	HLS-EU-Q47	Koltai and Kun (2016)

(continued)

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire (continued)

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Europe (continued)				
HLS-Italy	2015[b]	Supported by the pharmaceutical company MSD Italy	Department of Management & Innovation Systems, University of Salerno	Random sample, applying Eurobarometer methodology, PAPI
HLS-Switzerland	October-December 2015	Bundesamt für Gesundheit BAG	gfs.bern	Multi-stage random sample, CAPI
HLS-Israel	No information was found	Grant from the Israel National Institute for Health Policy Research	Department of Health Education and Promotion, Clalit Health Services, Tel Aviv, Israel	Random sample of Clalit Health Service members, face-to-face interviews
Health Information Sources study	March-April 2016	No information was found	Université Catholique de Louvain + Mutualité Chrétienne/Christelijke Mutualiteit	Internet survey
HLS-Norway	November 2014	Norwegian Nurses' Organisation, Inland Norway University of Applied Sciences and the Public Health Nutrition research group at Oslo Metropolitan University	Department of Public Health and Department of Nursing, Faculty of Social and Health Sciences, Inland Norway University of Applied Sciences	Telephone survey
Asia				
HLS-Taiwan	February-October 2013	Supported in part by Taiwan's Ministry of Science and Technology and Health Promotion Administration as well as research funding from Taipei Medical University, Shuang-Ho Hospital and Taipei Hospital, MOHW	Taipei Medical University, Taipei, Taiwan	Multi-stage stratification random sampling, similar to Eurobarometer methodology, interviewer-assisted self-report questionnaire
HLS-Japan	Spring 2013	Grant-in-Aid for Scientific Research from the Japan Society for the Promotion of Science (JSPS), KAKENHI Grant No 23390497	College of Nursing, St Luke's International University, Akashi-cho, Chuo-ku, Tokyo	Cross-sectional web-based anonymous health literacy questionnaire

	Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
	Italy	>18 years	1,000	HLS-EU-Q47	Palumbo et al (2016)
	Switzerland	≥15 years	1,107	HLS-EU-Q47	Bieri et al (2016)
	Israel	≥19 years	600 (Clalit Health Service members)	HLS-EU-Q16[c]	Levin-Zamir et al (2016)
	Belgium	≥18 years	5,711	HLS-EU-Q16	Avalosse et al (2017)
	Norway	≥16 years	900	HLS-EU-Q47[d]	Finbråten et al (2018)
	Taiwan	≥15 years	2,989	HLS-EU-Q47	Duong et al (2015)
	Japan	20-69 years	1,054	HLS-EU-Q47	Nakayama et al (2015)

(continued)

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire (continued)

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Asia (continued)				
HLS-Asia	2013-14	Taiwan's Ministry of Science and Technology and the Health Promotion Administration and MJ Health Research Foundation		Multi-stage stratification random sampling, similar to Eurobarometer methodology, interviewer-assisted self-report questionnaire *Taiwan:* community-based nationwide survey *Other five countries:* community-based city or regional surveys
HLS-Indonesia			Dian Nuswantoro University, Semarang, Indonesia	
HLS-Kazakhstan			Kazakhstan School of Public Health, Almaty, Kazakhstan, Kazakh National Medical University, Almaty, Kazakhstan	
HLS-Malaysia			University of Medicine, Yangon, Myanmar	
HLS-Myanmar			University Kebangsaan Malaysia, Selangor, Malaysia, University of Malaya, Kuala Lumpur, Malaysia	
HLS-Taiwan			School of Public Health, Taipei Medical University, Taipei, Taiwan, National Health Research Institutes, Miaoli County, Taiwan, Department of Family Medicine, National Taipei Hospital, MOHW, Taipei, Taiwan, Yuanpei University of Medical Technology, Hsin Chu, Taiwan	
HLS-Vietnam			Hai Phong University of Medicine and Pharmacy, Haiphong, Vietnam, Ha Noi University of Public Health, Hanoi, Vietnam	

Note: [a] The HLS-EU-Q47 was used in parallel to the HLQ, but HLS-EU-Q results have not been published. Results on the HLQ have been published in Bo et al (2014); [b] According to Rocco Palumbo; [c] Data were collected for all 47 HL items of the HLS-EU-Q47, but only the results from the HLS-EU-Q16 were reported; [d] A short version of the HLS-EU-Q47 was developed, the HLS-Q12 (Finbråten et al, 2018).

	Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
		≥15 years	10,024	HLS-EU-Q47	Duong et al (2017)
	Indonesia		1,029		
	Kazakhstan		1,845		
	Malaysia		1,600		
	Myanmar		462		
	Taiwan		3,015		
	Vietnam		2,073		

Conclusion and future developments

For research, policy and practice of public health, that is, for healthcare, disease prevention and health promotion, a comprehensive understanding of health literacy is valuable and a measurement instrument adequately reflecting this is instrumental. In this regard, the HLS-EU model and definition are highly relevant, and the HLS-EU instruments are a reliable and valid way of measuring the concept. The concept and instrument have been developed by a multinational consortium and have been tested and validated in a multinational study allowing for benchmarking of results. The general trends of health literacy in Europe and Asia have been demonstrated and specific situational/regional/national variations also shown. These kinds of results have stimulated public debate and political action to improve health literacy.

Concerning the future, preparations have begun for the next wave of a multinational European survey. As of spring 2018, an Action Network on Measuring Population and Organisational Health Literacy (M-POHL) within the European Health Indicators Initiative (EHII) of the European Office of WHO has been established and is preparing a population health literacy survey for 2019.

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