

# Executive Summary of the International Report on the Methodology, Results, and Recommendations of the European Health Literacy Population Survey 2019–2021 (HLS<sub>19</sub>) of M-POHL

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Chapters were written by extended author teams, which are named at the beginning of each individual chapter in the full report.

The full report can be found at <https://m-pohl.net/Results>

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# 1 Background/Introduction (Chapter1)

## Relevance of measuring HL in general adult populations and pre-existing research

The relevance of Health Literacy (HL) was first demonstrated for patients' utilization and the outcomes of health care services, primarily by research in the United States of America. The findings encouraged politicians to develop a national action plan for the improvement of HL and practitioners and researchers to develop the concept of a health-literate healthcare organization to deal better with patients with low HL.

Later, the importance of HL was also demonstrated for public health, more specifically for disease prevention and health promotion, and this in relation to the general population and not just for actual patients. In Europe, adult population HL was first measured in a few countries which participated in a US American led study, using the Health Activities Literacy Study (HALS) instrument, and in a single study in Switzerland, using a newly developed experience-based instrument.

The HLS-EU study (2009–2012) offered an integrated conceptual and generic model and definition of comprehensive General HL with a theory-based measurement instrument. Data were collected and analyzed, originally for eight European Union countries, but there were many follow-up studies in individual European countries and in a group of Asian countries. The results of these studies demonstrated the relevance of general, comprehensive HL for public health and health policy. Therefore, the WHO's report *Health Literacy: The solid facts* (2013) recommended the regular, standardized measurement of general population HL, as well as of organizational HL, to investigate how responsive health care and other organizations are to HL. The WHO's Action Network Measuring Population and Organizational Health Literacy (M-POHL) since 2018, followed up on this recommendation and initiated the Health Literacy Survey 2019–2021 (HLS<sub>19</sub>).

International and national policy documents have highlighted the relevance of HL and recommend measuring and improving HL in practice, both by investing in research and implementing HL policy. By that, global leaders in public health are paying increasing attention to the potential of HL. In 2009, the United Nations Economic and Social Council (ECOSOC) recognized the concept of HL as an "important factor for ensuring significant health outcomes" and called for action plans to promote it. Within the European Region, the WHO's publication *Health Literacy: The solid facts* (2013) summarized important evidence relating to the topic and highlights HL as a key dimension for implementing the WHO's European strategy Health 2020, not least in relation to its potential for promoting empowerment and participation in communities and in health care. At the WHO's 9<sup>th</sup> Global Health Promotion conference in Shanghai, China (2016), HL was prominently featured, resulting in the Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development, declaring HL a critical determinant of health. The Declaration established the link between HL and the United Nation's Sustainable Development Goals (SDGs), calling for the development, implementation, and monitoring of intersectoral strategies at national and local levels for strengthening HL in all populations. The Organisation for Economic Co-operation and Development (OECD) has also worked on HL, drafting a fast-track paper on how HL is addressed by OECD

Member States, which was published in 2018. Also in 2018, the Executive Board of the International Union of Health Promotion and Education (IUHPE) ratified a position statement, A Practical Vision for a Health Literate World, supporting HL policy, practice, and research at a global level. Specific attention has also been paid to the potential of HL to reduce the prevalence and impact of noncommunicable diseases (NCDs), as reflected in the Montevideo Roadmap 2018–2030 on NCDs as a Sustainable Development Priority. Within the European Region, former Regional Director Zsuzanna Jakab defined HL as one of the enablers for implementing the Sustainable Development Goals during the 67<sup>th</sup> WHO Regional Committee for Europe meeting in Budapest in September 2017. In 2019 the Region launched the resolution Towards the implementation of health literacy initiatives through the life course (EUR/RC69/R9) which demands, among others, the promotion of HL with a focus on reducing health inequities and the strengthening of HL measurements and action.

## 2 Methods

### 2.1 Study Design (Chapter 2)

In the HLS<sub>19</sub>, a cross-sectional multi-center survey study design was applied in 17 countries in the WHO European Region: Austria (AT), Belgium (BE), Bulgaria (BG), Czech Republic (CZ), Denmark (DK), France (FR), Germany (DE), Hungary (HU), Ireland (IE), Israel (IL), Italy (IT), Norway (NO), Portugal (PT), Russian Federation (RU), Slovakia (SK), Slovenia (SI) and Switzerland (CH).

The study population was defined as all permanent residents aged 18 and above, living in private households in the countries participating in the study. In total interviews from 42,445 respondents were included in the study. National sample sizes varied as follows: AT: 2,967, BE: 1,000, BG: 865, CH: 2,502, CZ: 1,599, DE: 2,143, DK: 3,602, FR: 2,003, HU: 1,195, IE: 4,487, IL: 1,315, IT: 3,500, NO: 2,855, PT: 1,247, RU: 5,660, SI: 3,360, and SK: 2,145.

The participating countries used a multi-stage random sampling procedure or quota sampling, and most countries stratified samples by gender, age group, population density, and geographical areas/units. As a rule, at least 80% of the HLS<sub>19</sub> core items, consisting of the 12 items measuring General HL and the 31 correlate items, needed to be answered to be accepted as a completed interview. Data collection was carried out in most of the participating countries by national data collection agencies and in three cases by the HLS<sub>19</sub> National Study Centers. The following methods of data collection were used: paper-and-pencil personal interviews (PAPI) in DE and RU; computer-assisted personal interviews (CAPI) in SK; computer-assisted telephone interviews (CATI) in AT, HU, IE, NO, and PT; and computer-assisted web interviews (CAWI) in BE, CH (with a few CATI), DK, and FR. There were also mixed types of data collection, namely CAWI + CATI (by CZ, IL, and IT) and CAPI + CAWI (by BG and SI). Response rates varied considerably across methods of data collection, from 4% (FR using CAWI) to 94% (RU using PAPI). Due to the Covid-19 pandemic, the original timeframe for collecting data was extended, and the data collection phase lasted from November 2019 to June 2021. All participating countries ensured compliance with ethical guidelines and data protection and explicitly obtained informed consent from respondents before carrying out any interviews.

Due to the differences in methodology, the time of data collection, and the potential effects of Covid-19, differences in results between countries, and any comparison among them, must be interpreted with caution.

### 2.2 The HLS<sub>19</sub> Instruments (Chapter 3)

To measure General HL, based on the HLS-EU instruments, an adapted 47-item instrument, the HLS<sub>19</sub>-Q47, and two adapted short forms, the HLS<sub>19</sub>-Q12 and the HLS<sub>19</sub>-Q16, were developed to

collect data. New instruments were developed to measure Digital HL, Communicative HL with physicians in healthcare, Navigational HL, Vaccination HL, and the Costs and Economics of HL, namely, respectively, the HLS<sub>19</sub>-DIGI, the HLS<sub>19</sub>-COM-P-Q11 (long form) and HLS<sub>19</sub>-COM-P-Q6 (short form), the HLS<sub>19</sub>-NAV, the HLS<sub>19</sub>-VAC, and an item set to measure HL and health-related quality of life as a mediator for health costs. Additionally, 31 core correlates, and 18 optional correlates were also made available in the HLS<sub>19</sub>. Participating countries had to implement at least the HLS<sub>19</sub>-Q12 and the 31 core correlates; all other parts were optional. National add-ons were possible. The HLS<sub>19</sub> instruments were translated into their national language(s) by 16 out of the 17 countries (Ireland used the original English version), thereby creating a rich spectrum of languages in which the instruments are now available: Arabic, Bulgarian, Czech, Danish, Dutch, French, German, Hebrew, Hungarian, Italian, Norwegian, Portuguese, Russian, Slovenian, and Slovak. Additionally, some countries translated the instruments into migrant languages. In 16 out of the 17 countries a field test was performed.

## 2.3 Methods of Data Analyses (Chapter 4)

Scores were calculated for the following HL measures:

HLS <sub>19</sub> -Q12	General Health Literacy (12 items)
HL-DIGI	Digital Health Literacy (8 items)
HL-DIGI-INT	Digital Interaction Literacy (2 items)
HL-NAV	Navigational Health Literacy (12 items)
HL-COM-Q11	Communicative Health Literacy with physicians in health care services (11 items)
HL-COM-Q6	Communicative Health Literacy with physicians in health care services (6 items short form)
HL-VAC	Vaccination Health Literacy score (4 items, which were all taken from the HLS <sub>19</sub> -Q47)

The score value was calculated as the percentage (ranging from 0 to 100) of items with valid responses that were answered with “very easy” or “easy”, provided that at least 80% of the individual items contained valid responses. Thus, the scores measure HL as the percentage of health-related tasks being experienced as “very easy” or “easy” by a respondent, with higher values indicating a higher level of General HL.

For General HL (HLS<sub>19</sub>-Q12), each respondent was assigned to one of four levels of HL: excellent, sufficient, problematic, or inadequate.

For each measure, the Cronbach alpha coefficient was calculated and a confirmatory factor analysis with a single latent variable as well as a Rasch analysis were conducted to confirm the internal consistency and the unidimensionality of the scale. For some measures of specific HL, this was complemented by models for two latent variables, or rather two dimensions.



Associations (1) between HL and a pre-defined set of potential determinants of HL or (2) between potential consequences or outcomes of HL and associated determinants were estimated by means of Spearman correlation coefficients and multivariable linear regression models. The following variables were analyzed as potential determinants: gender, age, education, self-perceived level in society, financial deprivation/difficulties, migration background, long-term illnesses/health problems, and training in a health care profession.

## 3 Key Results for General Health Literacy

### 3.1 The Instrument of measuring General HL (Chapter 5)

For the concept and definition of comprehensive, general HL, the HLS<sub>19</sub> followed the concept and definition of the HLS-EU, but instead of the long form Q47, the HLS<sub>19</sub> used a specially developed HLS<sub>19</sub>-Q12 shorter form to investigate General HL. (For those countries that used the Q47 or the Q22 data set for also constructing the Q16, data for the Q12 were extracted from this measure or data set.) The HLS<sub>19</sub>-Q12 measure represents the HLS-EU matrix by using one indicator for each cell; the wording of its items was adapted slightly and its answer categories to “very easy”, “easy”, “difficult”, and “very difficult”.

#### 3.1.1 Difficulty of Individual Items

To rank the individual items by difficulty, the response categories “very difficult” and “difficult” were combined. There were some common patterns for ranking the difficulties of HL-related tasks across countries, but there were also considerable differences between countries. The overall percentage of respondents ticking “very difficult” or “difficult” varied between 8% and 43% for the HLS<sub>19</sub>-Q12 items. On average, the most difficult tasks were item 3 “to judge the advantages and disadvantages of different treatment options” (42%, varying from 26% to 71%), item 8 “to decide how you can protect yourself from illness using information from the mass media” (40%, varying from 26% to 62%), item 5 “to find information on how to handle mental health problems” (36%, varying from 19% to 50%), and item 12 “to make decisions to improve your health and well-being” (26%, varying from 12% to 42%).

#### 3.1.2 Construction of Scores, Validation, and Psychometric Properties

The HLS<sub>19</sub>-Q12 shows adequate internal consistency, with an average Cronbach alpha coefficient of 0.78 (varying from 0.67 to 0.87 for individual countries). With the twelve dichotomized HLS<sub>19</sub>-Q12 items loading onto a single factor, the confirmatory factor model resulted in fit indices indicating a good model fit for each country. Three rather easy items differed considerably in relation to the standardized parameter estimates across countries. These were item 4 “to act on advice from your doctor or pharmacist” (“very difficult” or “difficult”, 8% on average, ranging from 4% to 17%), item 9 “to find information on healthy lifestyles such as physical exercise, healthy food, or nutrition” (9.9% on average, ranging from 6% to 21%), and item 10 “to understand advice concerning your health from family or friends” (17% on average, ranging from 7% to 27%).

When testing data against the Partial Credit Model (PCM) by country, the HLS<sub>19</sub>-Q12 displayed good overall data-model fit in eight participating countries. With a reduced sample size ( $n=360$ ), the HLS<sub>19</sub>-Q12 had acceptable overall data-model fit in an additional four participating countries. It had an acceptable reliability index in each country. The HLS<sub>19</sub>-Q12 was somewhat “off target” as the items referred to tasks which most respondents in the participating survey studies perceived as manageable.

Using a principal component analysis of Rasch model residuals, two possible subscales or item subsets of the HLS<sub>19</sub>-Q12 were identified empirically. However, these two subsets seem to measure “the same”, and so it may be concluded that the HLS<sub>19</sub>-Q12 is sufficiently unidimensional and measures one latent trait.

No evidence of response dependency or “too similar” items was observed. Most HLS<sub>19</sub>-Q12 items displayed acceptable data-model fit. Several items displayed differential item functioning (DIF) even when the sample size was reduced to 1,080. This could affect comparisons of subpopulations across countries, age groups, or employment status.

In conclusion, the HLS<sub>19</sub>-Q12 is a psychometrically rather sound instrument for measuring comprehensive General HL in adult populations as intended in the HLS<sub>19</sub>.

The statistical representation of the HLS<sub>19</sub>-Q47 by the HLS<sub>19</sub>-Q12 was tested in six countries with a Pearson correlation of 0.93 (ranging from 0.90 to 0.95 for individual countries). Accordingly, the HLS<sub>19</sub>-Q12 represents the total score of the HLS<sub>19</sub>-Q47 very well from a statistical perspective.

### 3.1.3 Distributions of Scores and APRPs

The distribution of the scores was negatively (left) skewed for all countries. There was also a considerable ceiling effect, which partly indicates that the scale included tasks that many respondents found manageable. Thus, the instrument is sensitive especially for respondents with lower HL.

For all countries, the median score of the HLS<sub>19</sub>-Q12 was 83, varying across countries from 67 to 91; the mean score was 76 and varied across countries from 65 to 86.

The ceiling effect and its variation across countries was also shown by the Average Percentage Response Patterns (APRPs) for HLS<sub>19</sub>-Q12, where, on average, 24% answered the items as being either “very difficult” or “difficult” (varying from 14% to 35% between countries).

Based on defined cutting points, like those in the HLS-EU, categorical levels were constructed for the HLS<sub>19</sub>-Q12. Accordingly, across all participating countries, about 40% of respondents had a “sufficient” level of HL, with about 15% being “excellent”. In contrast, about 33% had a “problematic” level and for 13% it was “inadequate”. There was considerable variation in level values across countries. Following the example of the HLS-EU study, the HL categorical levels of “inadequate” and “problematic” were combined and defined as “limited” HL, with a range of 25% to 72%. That

means that between one in four and three out of four residents in countries participating in the HLS<sub>19</sub> have limited General HL. Compared to the HLS-EU, with one out of three up to two out of three, the variation between countries is even more pronounced, which could be due to the different methodology used but also by different countries being included in the two studies.

### 3.1.4 Disadvantaged/Vulnerable Subpopulations

The HLS<sub>19</sub>-Q12 mean score was considerably lower for selected predefined disadvantaged or vulnerable subpopulations than for the total population. This was, on average, especially true for respondents with “poor self-perceived health” (-14%, varying across countries from -5 to -27), respondents who are “financially deprived” (-8%, varying from +1 to -14), respondents reporting a “low self-perceived level in society” (-8%, varying from -2 to -18), or respondents with “low education” (-6% points, varying from +1 to -22).

## 3.2 Social Gradient and Determinants (Chapter 6)

To investigate the social gradient, indicators were used including gender, age, education, self-perceived level in society, and financial deprivation. The existence of a social gradient was confirmed by multivariable linear regression models explaining on average 7% of the variance of the HLS<sub>19</sub>-Q12 score, ranging from 4% to 25% across countries. The strongest predictors of the social gradient were financial deprivation, with, on average,  $\beta = -0.21$  (varying from  $\beta = -.15$  to  $\beta = -0.32$  and significant ( $p < 0.01$  is referred to here and elsewhere in this summary) for all countries with one exception), followed by the respondents’ self-perceived level in society, with  $\beta = 0.10$  (significant for 14 countries and varying for these from  $\beta = 0.08$  to  $\beta = 0.26$ ).

Models including additional predictors (respondents’ migration background, long-term illness, training in a health care profession) did not, on average, improve the explained variance of the models. In fact, respondents’ migration background had a significant effect on HL in just two countries (with migrants having a slightly higher level of General HL in those two countries), long-term illness in eight countries (respondents with at least one long-term illness having lower General HL), and training in a health profession in eight countries (respondents trained in a health profession having higher General HL).

Thus, the HLS<sub>19</sub> confirms earlier results that there is a social gradient for General HL across countries which varies to a considerable extent and that both financial deprivation and level in society are the strongest predictors.

## 3.3 Consequences for Health-Related Outcome Indicators

### 3.3.1 Health Behaviors and Lifestyles (Chapter 7)

The potential effects of General HL on five indicators – BMI, smoking behavior, alcohol consumption, physical activity, and fruit and vegetable consumption – were investigated. Multivariable linear regression models showed significant effects of General HL on physical activity explaining, on average, 3% of the variance (varying across countries from 1% to 9%) with, on average,  $\beta=0.11$  (significant for 12 countries, varying for these from  $\beta=0.08$  to  $\beta=0.27$ ). Compared to the five social indicators, General HL is the strongest predictor of physical activity. For fruit and vegetable consumption, the same models explained 4% of the variance on average (varying from 4% to 9% across countries), with General HL being the second strongest predictor at  $\beta=0.09$  (significant for eight countries, varying for these from  $\beta=0.07$  to  $\beta=0.18$ ). However, while similar models explained 5% of the variance for BMI, (varying from 1% to 14%), General HL was the predictor with the lowest  $\beta$  on average, at  $\beta=-0.01$  (and was significant for only two countries at  $\beta=-0.06$ ). For smoking behavior, similar models explained, on average, 4% of the variance (varying from 1% to 14%); the results for General HL were significant, but inconsistently so, for only four countries, with either  $\beta=-0.04$  and  $\beta=-0.06$  or  $\beta=+0.08$  and  $\beta=+0.09$ ). For alcohol consumption, similar models explained 8% on average (varying from 5% to 16%), with General HL showing on average a low  $\beta=-0.05$ , which was significant for only five countries:  $\beta$  ranged from  $-0.05$  to  $-0.13$  in four countries but for the fifth  $\beta=+0.09$ , which was in an unexpected direction.

Thus, according to the HLS<sub>19</sub>, General HL was shown to have potentially positive effects on only two lifestyle indicators, namely physical activity and fruit and vegetable consumption. In contrast to some earlier research, no relevant and consistent effects on BMI, smoking behavior, and alcohol consumption could be demonstrated for most countries.

### 3.3.2 Health Status (Chapter 8)

The three Minimum European Health Module (MEHM) indicators (self-perceived health, long-term illness/health problems, and limited in activities due to long-term illness/health problems) were used to investigate the potential effects of General HL on respondents' health status. In all countries (equally weighted), a positive linear association was found between General HL and self-perceived health, while negative linear associations were demonstrated between General HL and long-term illness/health problems as well as between General HL and limited in activities due to long-term illness/health problems. These associations varied considerably in extent (and consistency) across participating countries.

In multivariable linear regression models for self-perceived health, including the five core social indicators and General HL as predictors, on average, 21% of the variance (varying from 11% to 38%), was explained, with General HL being the predictor with the third highest  $\beta=-0.15$  (varying

from  $\beta=-0.07$  to  $\beta=-0.22$ ; significant for each country). Similar models for long-term illnesses/health problems explained 15% of the variance on average (varying across countries from 8% to 37%), with General HL again being the third highest predictor on average at  $\beta=-0.09$  (significant for seven countries, varying for these from  $\beta=-0.06$  to  $\beta=-0.19$  across countries). For being limited in activities due to health problems, the models explained, on average, 10% (varying from 3% to 22%), and General HL was the predictor with the second highest  $\beta=0.14$  on average, (significant for 13 countries, varying for these from  $\beta=0.06$  to  $\beta=0.21$ ).

Thus, this study confirmed earlier research that there is a potentially direct, relevant effect of General HL on respondents' health status. This pattern applied to most of the countries, with some variation in extent for the different health status indicators.

### 3.3.3 Extent of Healthcare Services Utilization (Chapter 9)

The potential effects of General HL on the extent of the utilization of healthcare services were investigated for five types of health services (emergency services, GPs/family doctors, medical or surgical specialists, inpatient hospital service, and day-patient hospital service).

Multivariable linear regression models, with General HL and five social indicators as predictors, explained just 2% of the variance on average (varying from 1% to 11%) for the utilization of emergency services, with General HL being the second highest predictor on average, at  $\beta=-0.06$  (significant for eight countries and varying for these from  $\beta=-0.05$  to  $\beta=-0.20$ ). Similar models for the utilization of GPs/family doctors explained, on average, 6% of the variance (varying from 4% to 14%), with General HL being the predictor with the second highest  $\beta=-0.09$  on average (significant for nine countries, varying for these from  $\beta=-0.05$  to  $\beta=-0.14$ ). For the utilization of medical and surgical specialists, similar models explained, on average, 3% of the variance (varying from 1% to 12%), with General HL being the predictor with the fourth highest significant  $\beta=-0.05$  on average (but significant for only four countries and varying for these from  $\beta=-0.05$  to  $\beta=-0.10$ ). Similar models for the utilization of inpatient hospital services explained, on average, just 2% of the variance (varying from 0% to 9% across countries), with General HL, on average, being the third highest predictor at  $\beta=-0.04$  (significant for just four countries and varying for these from  $\beta=-0.05$  to  $\beta=-0.06$ ). For the utilization of day patient hospital services, the models explained, on average, just 1% (varying from 1% to 4%), with General HL, on average, being the predictor with the second highest significant  $\beta=-0.04$  (significant for only two countries, varying from  $\beta=-0.04$  to  $\beta=-0.06$ ).

Thus, as expected from earlier research, a potentially direct, relevant effect of General HL on the utilization of health care services could be demonstrated just for specific indicators and for a smaller number of countries. While regression models did not explain much of the variance introduced by the classical social determinants included, in comparison to these, General HL was relatively relevant and is a better modifiable predictor of health care service utilization.

## 4 Specific Health Literacy Measures

In contrast to the HLS–EU study, in the HLS<sub>19</sub>, besides measuring General HL, optional work packages were included for especially relevant specific aspects of HL, namely Navigational HL, Communicative HL with physicians, Digital HL, and Vaccination HL. These were developed and validated jointly, translated, and administered for the first time, with 12 countries participating in Digital HL, nine countries in Communicative HL with physicians in health care services, eight countries in Navigational HL, and 11 countries in Vaccination HL.

### 4.1 Navigational HL (Chapter 10)

#### 4.1.1 Relevance

In the last few decades, the structures, and regulations of healthcare systems in many countries have become increasingly complex for patients and users and thus ever more difficult for them to navigate. Thus, more than ever before, specific Navigational HL is needed by patients and users alike. In response to a lack of measurement tools and population–based data on Navigational HL, one aim of the HLS<sub>19</sub> was to develop and introduce a theory–based instrument for measuring Navigational HL and to provide data on the topic by the same instrument in a set of different countries for the first time.

#### 4.1.2 Definition and Instrument

Using the conceptual framework of the HLS–EU Consortium and the HLS<sub>19</sub> study, Navigational HL was defined as “people’s knowledge, motivation and skills to access, understand, appraise and apply the information and communication in various forms necessary for navigating healthcare systems and services adequately to get the most suitable health care for oneself or related persons”. An instrument for measuring Navigational HL was developed based on a scoping review of the literature, an expert and stakeholder survey, focus group discussions, personal interviews, and continuous discussions in the HLS<sub>19</sub> Consortium. This led to a questionnaire with twelve items measuring self–perceived difficulties in accessing, understanding, appraising, and applying navigation–related information primarily for selected tasks on the macro (societal) and meso (organizational) levels of navigating health care services.

### 4.1.3 Data Collection

The Navigational HL was applied in eight countries (AT, BE, CH, CZ, DE, FR, PT, and SI) in seven languages in samples using CATI, CAWI, or mixed methods for data collection for a total of over 16,000 respondents.

### 4.1.4 Difficulty of Individual Items

The percentages of the combined “difficult” or “very difficult” answers to the 12 HLS<sub>19</sub>-NAV items ranged from 19.5 % to 56.6 %, with considerable variation across countries. The most difficult tasks were dealing with information on health care reforms, the suitability of a particular health service, patients’ rights, and health insurance coverage of specific health services.

### 4.1.5 Construction of Scores, Validation, and Psychometric Properties

A score for Navigational HL was calculated by combining the response categories “very easy” or “easy”, adding these up over the twelve items, and standardizing the raw score for a range from 0 to 100. The scale proved to be a valid measure with acceptable psychometric properties concerning internal consistency (Cronbach’s alpha between 0.83 and 0.92), and unidimensionality by CFA and polytomous partial credit Rasch models. Nevertheless, the instrument worked better in some countries than in others, and limitations exist regarding differential item functioning (DIF). With correlations on average between 0.40 and 0.56 with the other specific HLs and General HL, the instrument is related closely enough to be interpreted as being an instrument of HL and independent enough to measure a specific aspect of HL.

### 4.1.6 Distributions of Scores and APRPs

With, on average, a mean score of 55 (varying from 42 to 67), Navigational HL is low in most countries, at least compared to the measures of other health literacies. In terms of Average Percentage Response Patterns, 45% of the answers (varying from 33% to 59% across countries) were, on average, either “very difficult” or “difficult”.

### 4.1.7 Disadvantaged/Vulnerable Subpopulations

In most countries, participants with poorer health (on average –12%), financial deprivation (–10%), and self-perceived level in society (–9%) had mean scores for Navigational HL which were considerably below the population’s average.



## 4.1.8 Social Gradient and Determinants

In multivariable linear regression models with five social determinants, explaining, on average, 6% of the variance (from 4% to 13% across countries), a social gradient was demonstrated for Navigational HL, with, on average, financial deprivation ( $\beta=-0.15$ ), self-perceived level in society ( $\beta=0.14$ ), and education ( $\beta=-0.11$ ) being the predictors with the highest  $\beta$  values. When General HL was also introduced into the regression model, General HL was found to be the strongest predictor with, on average,  $\beta=0.53$ .

## 4.1.9 Consequences for Health-Related Outcome Indicators

With similar regression models, higher HL-NAV was a significant predictor of self-perceived health with, on average,  $\beta=-0.13$  (significant in seven out of the eight countries and varying for these from  $\beta=-0.06$  to  $\beta=-0.13$ ). For limited in activities due to health problems this was the case, with, on average,  $\beta=0.11$  (significant for only five countries and varying for these from  $\beta=0.07$  to  $\beta=0.10$ ) and for long-term illnesses or health problems, with, on average,  $\beta=-0.07$  (significant for only two countries, with  $\beta=-0.06$  to  $\beta=-0.10$ ). For indicators of utilization of GPs/family doctors, and utilization of medical and surgical specialists, navigational HL was a significant indicator for only two or one countries.

## 4.1.10 Discussion and Conclusions

With the HLS<sub>19</sub>-NAV, a new and extensively tested instrument with some potential for improvement is available, the implementation of which has provided important information for the specific field of managing health information in the context of navigating healthcare systems. The results confirm the need to strengthen Navigational HL (and General HL) through target group-specific, tailored strategies but also to reduce the demands placed on individuals by realizing health-literate healthcare systems and anchoring Navigational HL at all levels of the system.

## 4.2 Communicative HL with Physicians (Chapter 11)

### 4.2.1 Relevance

Communicative HL is recognized as being critical for patients to actively participate in health communication with health professionals, to obtain and understand information, to achieve successful

outcomes from health care, and to use the information to manage health. Communication is a core task for health professionals and patients when making diagnosis, deciding on and implementing treatments, organizing appropriate health care, and maintaining good health. Communication in health care settings is becoming increasingly important due to changes in the patients' role, the expectation for more patient participation and for shared decision making. But for a start, the working group on this optional package developed an instrument just for Communicative HL with physicians.

## 4.2.2 Definition and Instrument

A comprehensive definition of Communicative HL is provided: "Communicative HL refers to patients' communicative and social skills that enable them to actively engage in face-to-face encounters with health care professionals, to give and seek information, derive meaning from it and apply this information in decision making and in co-producing their health care". However, the focus of this instrument is on physician-patient communication within the healthcare system. For this, a long form (11 items) and a short form (6 items) were constructed based on a comprehensive theoretical framework that integrates the communicative literacy concept of Nutbeam, the basic competencies of information processing included in the HL framework of the HLS-EU Consortium), and the main communicative tasks of the Calgary-Cambridge Guide framework.

## 4.2.3 Data Collection

The HLS<sub>19</sub>-COM-P instrument was successfully applied in nine countries: Austria, Belgium, Bulgaria, Czech Republic, Germany, Denmark, France, Hungary, and Slovenia, in seven languages (in a total sample of around 20,000 for the HLS<sub>19</sub>-COM-P-Q6) using different formats of data collection (PAPI, CATI, CAWI, or mixed methods).

## 4.2.4 Difficulty of Individual Items

Perceived difficulties ranged on average from 4% to 25% for the HLS<sub>19</sub>-COM-P-Q11 items and from 9% to 26% for the HLS<sub>19</sub>-COM-P-Q6 items. In general, getting enough time in the consultation with the physician and expressing personal views and preferences were experienced as being the most difficult tasks, while explaining personal health concerns was the easiest.

## 4.2.5 Construction of Scores, Validation, and Psychometric Properties

Scores for the long and short scales of Communicative HL were calculated by combining the response categories “very easy” and “easy”, adding these up over the eleven or six items respectively, and standardizing the raw scores for a range from 0 to 100. Both instruments displayed acceptable psychometric properties for internal consistency with Cronbach’s alpha (for HLS<sub>19</sub>-COM-P-Q11: mean 0.83, from 0.79 to 0.87; for HLS<sub>19</sub>-COM-P-Q6: mean 0.78, from 0.69 to 0.81), as well as for unidimensionality by CFA and polytomous partial credit Rasch models. Both instruments correlated moderately with General HL (mean 0.46 and 0.43 respectively) and with Navigational HL (mean 0.47 and 0.43 respectively), indicating that Communicative HL and General HL or Navigational HL are related but still distinctive constructs.

## 4.2.6 Distributions of Scores and APRPs

For all countries, the distributions of scores were rather left-skewed. Communicative HL with physicians, in the general population under investigation, was relatively good with a mean score for Q11 of 85 (ranging from 74 to 92) and a mean score for Q6 of 83 (from 72 to 90), but about 10–20% of the population have problems communicating with their physician. In terms of APRPs, 15% (from 8% to 26%) of the answers for the Q11 or 17% (from 9% to 27%) of the Q6 were either “very difficult” or “difficult”.

## 4.2.7 Disadvantaged/Vulnerable Subpopulations

In most countries, participants with poorer self-perceived health (on average –11%) or lower socioeconomic status (financial deprivation (–9%) and self-perceived level in society (–8%)) were found to have lower Communicative HL mean scores than their national population.

## 4.2.8 Social Gradient and Determinants

In multivariable linear regression models with five social determinants for the short form of Communicative HL, explaining on average 5% of the variance (varying across countries from 2% to 18%) a social gradient was identified for Communicative HL, with, on average, level in society ( $\beta=0.14$ ), financial deprivation ( $\beta=-0.13$ ), and education ( $\beta=-0.07$ ) being the predictors with the highest  $\beta$  values. When General HL was also introduced into the regression model, General HL was found to be the strongest predictor with, on average,  $\beta=0.42$ .

## 4.2.9 Consequences for Health-Related Outcome Indicators

In most countries Communicative HL was a significant predictor of self-perceived health, while in some countries higher Communicative HL was associated with somewhat lower use of medical care.

## 4.2.10 Discussion and Conclusions

The HLS<sub>19</sub>-COM-P instrument was used successfully in research on different national adult general populations to map communicative HL. Physician-patient communication is an important aspect of HL and a relevant issue for health policy and practice. It is of utmost importance for patient satisfaction and participation but also for health outcomes and health equity. The restriction of the study to physician-patient interaction indicates that further research is needed for Communicative HL focusing on other health professionals.

## 4.3 Digital HL (Chapter 12)

### 4.3.1 Relevance

The increasing availability and use of health-related digital/electronic resources such as electronic health records, telehealth initiatives, digital health applications, and interactive communication options with health care providers (e.g., for making appointments or reporting medical results) places a growing demand on the population's skills in relation to Digital HL to adequately use these applications and resources. Researchers, practitioners, and policy makers should therefore realize the importance of understanding and improving people's proficiency in using digital resources for managing disease and/or promoting their health by measuring Digital HL.

### 4.3.2 Definition and Instrument

The concept and definition of Digital HL in the HLS<sub>19</sub> is based on the HLS-EU Consortium's concept and definition of General HL but aligned with existing research on the scope and diversity of digital health resources. Digital HL includes the ability to search for, access, understand, appraise, validate, and apply online health information as well as the ability to formulate and express questions, opinion, thoughts, or feelings when using digital devices. This concept relates strongly to the frequency with which people use different health resources from digital sources and resources

such as online video consultations, digital personal health records, social media, and health related apps, etc. for promoting health. One scale was constructed with eight items measuring the skills related to dealing with health information digitally and two items for the interactive use of digital devices.

### 4.3.3 Data Collection

The following countries included the optional package on Digital HL in their national assessment: Austria, Belgium, Czech Republic, Denmark, France, Germany, Hungary, Ireland, Israel, Norway, Portugal, Slovakia, and Switzerland. Analyses were based on 29,060 respondents, with country specific sample sizes ranging from 1,000 to 3,602. There was variation in the data collection method administered, by using CAPI, CATI, CAWI, PAPI, and mixed formats.

### 4.3.4 Difficulty of Individual Items

The ranked difficulty of single tasks across countries is rather similar, with some exceptions. On average, the difficulty of items varies (for the combined response categories “very difficult or “difficult”) between 22% and 54%, with considerable variation across countries. The three most difficult tasks were: “to judge whether the information is reliable”, “to judge whether the information is offered with commercial interests”, and “to use the information to help solve a health problem”.

### 4.3.5 Construction of Scores, Validation, and Psychometric Properties

A score was calculated for Digital HL by combining the response categories “very easy” and “easy”, adding them up across the eight items, and standardizing the raw score for a range from 0 to 100. The internal consistency of the Digital HL scale is acceptable with, on average, Cronbach’s alpha of 0.83, varying across countries from 0.77 to 0.87. A single-factor confirmatory factor model with dichotomized items loading onto a single latent variable provided fit indices which indicate an acceptable fit for all countries. According to a principal component analysis (PCA) of Rasch model residuals combined with dependent t-tests to identify possible empirical subscales, the Digital HL scale was sufficiently unidimensional. The thresholds, and thus the response categories, were ordered and well-functioning. On average, Digital HL correlated with General HL ( $r=0.53$ ), Navigational HL ( $r=0.55$ ), Communicative HL (Q11:  $r=0.39$ , Q6:  $r=0.31$ ), and Vaccination HL ( $r=0.38$ ), and was thus related enough to the other HLs to measure HL and independent enough to measure a specific aspect of HL.

### 4.3.6 Distributions of Scores and APRPs

For all but one country, the distributions of Digital HL scores were left-skewed, with a clear ceiling effect. The mean score was, on average, 62, varying from 42 to 79 across countries. In terms of the APRPs, on average, 38% of the answers were either “very difficult” or “difficult”, varying between 22% and 58% across countries.

### 4.3.7 Disadvantaged/Vulnerable Subpopulations

Disadvantaged or vulnerable subpopulations with lower mean scores of Digital HL than the national population were identified as respondents with bad or very bad self-perceived health (on average -11%), with considerable or severe financial deprivation (-9%), with low education (-8%), with six or more contacts to a GP/family doctor (-7%), and with low self-perceived level in society (-7%).

### 4.3.8 Social Gradient and Determinants

A social gradient for Digital HL was demonstrated by multivariable linear regression models with five social predictors; explained variance varied by country (6% on average, varying from 2% to 23%). On average, financial deprivation was the predictor with the highest  $\beta = -0.15$  (significant with  $\beta$  between -0.08 and -0.27 for 10 countries), followed by age with  $\beta = -0.13$  (significant for six countries with  $\beta$  between -0.15 and -0.26), self-perceived level in society with  $\beta = 0.08$  (significant for 10 countries with  $\beta$  between 0.05 and 0.13). Including the extent of use of digital resources in the model did not improve explained variance much, but the use of digital resources with, on average,  $\beta = 0.11$  (significant for 10 countries with  $\beta$  between 0.06 and 0.22) was the predictor with the third highest value, after financial deprivation and age. When General HL is also included in the original model, it is by far the strongest predictor of Digital HL with  $\beta = 0.51$  (significant for all countries, varying from  $\beta = 0.43$  to  $\beta = 0.67$ ), followed by age ( $\beta = -0.13$ ), financial deprivation ( $\beta = -0.06$ ), and education ( $\beta = 0.06$ ).

### 4.3.9 Consequences for Health-Related Outcome Indicators

In a multivariable linear regression model for explaining self-perceived health with the five social determinants and Digital HL as predictors, Digital HL was significant for nine out of 13 countries (with  $\beta = -0.05$  or  $-0.10$ ). A similar model for the utilization of GPs/family doctors as dependent variable showed significant effects of Digital HL for seven countries ( $\beta$  between -0.07 and -0.11).

### 4.3.10 Discussion and Conclusions

A new, short eight-item scale for measuring experience-based Digital HL was jointly developed, validated, and used for investigating Digital HL in thirteen countries. The measure showed acceptable psychometric properties for all countries, but further development is recommended. The results demonstrated the relevance of Digital HL by revealing that a considerable proportion of respondents have lower Digital HL, that there is a social gradient for Digital HL in most countries, and that Digital HL is associated with the health-relevant indicators self-perceived health also in most countries and with utilization of GPs/family doctors in some countries. By identifying especially difficult, concrete tasks relating to Digital HL and subpopulations with lower Digital HL than the national adult population, the results offer an orientation for tailoring strategies to improve Digital HL by health policy.

## 4.4 Vaccination HL (Chapter 13)

### 4.4.1 Relevance

Vaccine hesitancy is a pressing public health issue, especially in Europe, and it poses an increasing challenge to health authorities. Credible and tailored information about vaccination could help regain individuals' confidence in vaccinations. However, as information on vaccination is often difficult to access, complex, not always easy to understand, and challenged by biased and one-sided information, a high level of Vaccination HL is a prerequisite for assessing the trustworthiness and quality of information and for dealing competently with false and misleading information.

### 4.4.2 Definition and Instrument

Based on the definition of General HL the working group defined Vaccination HL as referring to people's knowledge, motivation, and skills to find, understand, and evaluate immunization-related information to make informed decisions on immunization. A context-independent measure of Vaccination HL was developed, measuring the process dimensions of finding, understanding, judging, and applying vaccination information for better immunization, based on a partial adaptation of the four vaccination-related items included in the HLS-EU survey. In addition, the optional package on HL-VAC also included one item on personal vaccination behavior during the last five-year period, four items referring to personal confidence in vaccinations (Confidence), three items on myths about possible risks of getting vaccinated (Calculation/Conspiracy), and one item on the risk of getting a disease for which a vaccine exists if not vaccinated (Complacency).

### 4.4.3 Data Collection

Seven countries (AT, BE, CZ, HU, IE, PT, SI) implemented the complete optional package on Vaccination HL, and four additional countries (BG, DE, IT, and NO) collected data on at least the four HL-VAC items and general background variables. Differing by country, data were collected by PAPI, CAPI, CATI, and CAWI, or combinations of these. In total, data on Vaccination HL are available for just over 25,000 respondents in Europe.

### 4.4.4 Difficulty of Individual Items

There was a rather common ranking of difficulty of the four items across countries, with “judging which vaccinations you or your family needs” as the most difficult item, followed by “finding information on recommended vaccinations”, “deciding if you should have a flu vaccination”, and “understanding why you or your family may need vaccinations”.

### 4.4.5 Construction of scores, Validation, and Psychometric Properties

A score was calculated for Vaccination HL by combining the response categories “very easy” and “easy”, adding these up over the four items, and standardizing the raw score for a range from 0 to 100. The internal consistency of the Vaccination HL scale with an, on average, Cronbach’s alpha of 0.72, varied between 0.60 and 0.85, indicating that the reliability of the scale is acceptable for most countries. Confirmatory factor and discriminant analyses revealed that the HL-VAC measures a different but related trait or competencies than the overall HL scale (HLS<sub>19</sub>-Q12). The overall data-model fit to the Rasch model was sufficient for the Vaccination HL scale for five countries, acceptable for four countries, but poor for two countries. The scale did not measure invariantly across countries since the “difficulty order” of the items varied between countries.

### 4.4.6 Distributions of Scores and APRPs

The distribution of the Vaccination HL score was negatively skewed across all countries, suggesting a ceiling effect. The mean score for all countries (equally weighted) was 75, varying from 58 to 87. In terms of APRPs, on average 25% of the responses rated the Vaccination HL items as either “very difficult” or “difficult”, varying between countries from 13% to 45%.



#### 4.4.7 Disadvantaged/Vulnerable Subpopulations

Respondents with low education (in six countries), low self-perceived level in society in ten countries), some or severe financial deprivation in all 11 countries), and limited by health problems (in eight countries) had lower Vaccination HL mean scores compared to the corresponding comparison groups.

#### 4.4.8 Social Gradient and Determinants

In multivariable linear regression models with five potential social determinants, there is a weak social gradient for Vaccination HL, with financial deprivation being the predictor with the highest  $\beta = -0.17$  on average (significant for all but one countries), followed by level in society ( $\beta = 0.05$ , significant for three countries), and education ( $\beta = -0.04$ , significant for five countries). In a model with General HL added, General HL is by far the predictor with the highest  $\beta = 0.51$  (varying across countries from  $\beta = 0.39$  to  $\beta = 0.70$ ).

#### 4.4.9 Consequences for Health-Related Outcome Indicators

In all but one country, Vaccination HL is positively correlated with confidence in vaccinations, knowledge about the risks of vaccines, and risk assessment of developing a specific disease if not vaccinated. Vaccination behavior, defined as the odds of someone in the family being vaccinated in the last five years, increased as a function of Vaccination HL for five out of seven countries, when controlling for socio-demographic and socio-economic variables, and being trained in a health profession. Mediation analysis using the Baron and Kenny approach showed that the relationship between Vaccination HL and vaccination behavior is at least partly mediated by confidence in vaccinations, risk knowledge, and risk perception.

#### 4.4.10 Discussion and Conclusions

As such, the measure is suitable for measuring Vaccination HL in different countries but could be further developed with a focus on additional, specific HL-VAC tasks. The results demonstrated the relevance of Vaccination HL by revealing that a considerable proportion of respondents have lower Vaccination HL, that there is a social gradient for Vaccination HL in most countries, and that Vaccination HL is associated with vaccination behavior in most countries.

## 4.5 Health literacy and health-related quality of life as a mediator for health costs (Chapter 14)

### 4.5.1 Relevance

The objectives/research questions of this chapter were twofold: first to explore whether there is a relationship between general, comprehensive HL (as measured by HLS<sub>19</sub>-Q12), and health-related quality of life (as measured by EQ-5D-5L), and secondly to explore the relationship between HL and work absenteeism.

Both health-related quality of life and absenteeism have cost and economic implications for health services, for individuals and for society. Such costs are in the context of rising health care expenditure and limited health budgets globally. The findings provide evidence to inform policy makers of the importance of interventions to enhance HL as a disease prevention strategy so as to improve health-related quality of life and reduce the incidence of absenteeism amongst citizens. Such outcomes will assist in more efficient use of scarce resources for health care expenditure, a better quality of life for citizens, with consequent implications for society.

### 4.5.2 Specific Instruments and Indicators

Health Related Quality of life (HRQoL) denotes the impact of health on a person's ability to live a fulfilling life, defined by the World Health Organisation (WHO) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. HRQoL thus represents a broad concept of physical, psychological, and social functioning and well-being including both positive and negative aspects.

Absence from work was measured by the number of days of absenteeism per year due to health problems.

### 4.5.3 Data Collection

Specific data for this chapter was collected for the measure EQ-5D-5L in three countries Denmark, Ireland, and Norway. Differing by country, data were collected by CATI (Ireland and Norway) and CAWI (Denmark). In total data on EQ-5D-5L are available for nearly 6,000 respondents in the three countries.

## 4.5.4 Method

A freely available English syntax file for transforming the responses to the EQ-5D-5L questionnaires into an EQ-5D-5L estimate for individual respondents was used. For regression analyses with EQ-5D-5L as the dependent outcome variable, it was relied on Ordinary Least Squares (OLS) estimation with “robust” estimates of variance to account for violations of homoscedasticity.

The analysis of number of days of absenteeism per year due to health problems was based on the two-step model (“Two-part model”) where the first step is based on “probit” and the second step on General Linear Modelling (GLM) with gamma “distribution family”, log link function and “robust” estimation of variance.

## 4.5.5 Results

### Research Question 1

The analysis of Health-Related Quality of Life (HRQoL), as measured by EQ-5D-5L, in the three countries Denmark, Ireland and Norway, shows a significant association between General HL and health related quality of life. In general, as HL increases so does HRQoL.

The magnitude of the association between General HL and HRQoL is larger than that for the association between education and HRQoL highlighting the importance of HL interventions to improve General HL levels for adult populations. The associations observed between HRQoL and General HL and other social determinants of health appears to be additive for education level, gender and employment status.

### Research Question 2

For both Norway and Denmark, a negative correlation between HL and absenteeism was observed. As General HL increases there is a decrease in absenteeism from work due to health problems. For Ireland when General HL score increases from 0 to about 70, absenteeism increases, however absenteeism decreases thereafter, noting that 73% of the respondents have a General HL score between 70% – 100%. These findings suggest that further research and analysis of the HLS<sub>19</sub> international data is required to fully understand the complexities surrounding the correlation between HL and absenteeism from the workplace.

## 4.5.6 Discussion/Conclusion/Recommendations

This is the first European study to explore and measure the relationship between General HL (as measured by HLS<sub>19</sub>-Q12), and health-related quality of life (as measured by EQ-5D-5L) which have consequential cost and economic implications for the health services, for individuals and for

society. The sample size within this study is large across the three countries where the health-related quality of life data were collected for EQ-5D-5L. Unlike prior studies of the health economic implications of HL all the data were directly measured, with no data inferred.

The findings of the HLS<sub>19</sub> study are sufficiently strong for national and local governments to recognise the importance of General HL for the health and well-being of their citizens and in the utilization of health services. Investment in HL interventions as a disease prevention strategy at local, national and regional levels may lead to significant benefits to citizens for their quality of life alongside more effective use of expensive health services.

## 5 Recommendations

One of the aims of the HLS<sub>19</sub> was to gather evidence to inform policy, practice, and further research. The data allow to distinguish aspects and domains of HL that need more attention than others. The same holds true for different population groups, identifying those at the lower end of the social gradient who are in more need of support in relation to their HL. The data, however, do not provide evidence for specific concrete interventions to address the areas that need to be improved.

On these grounds, the HLS<sub>19</sub> consortium agreed on a set of recommendations, presented here in a shortened format.

### Regarding General HL

- » Health policy should include an investment in longitudinal studies, measuring and monitoring population HL regularly, and should systematically implement interventions to improve HL.
- » Interventions should be specifically targeted at at-risk groups for low HL to reduce the health gap between groups.
- » Interventions to improve HL should focus on all four aspects of processing health-related information (accessing, understanding, appraising, and applying information) within the domains of healthcare, disease prevention, and health promotion.
- » For interventions related to specific, concrete HL tasks, the tasks that are experienced as being more difficult should be prioritized.
- » The quality of health information in the mass media should be improved.
- » Interventions to improve HL in relation to mental health should be prioritized and supported by specific research.

### Regarding specific HLs

- » Health policy should develop strategies to improve people's Navigational HL, specifically interventions on systemic and organizational levels to make health systems more health-literate, user-friendly, and easier to navigate.
- » Interventions to improve the communication of health professionals with patients should have high priority. Specifically, support for health professionals, especially physicians, in dedicating more time to person-centered communication is needed.
- » Regarding Digital HL, emphasis on providing easily accessible, high quality, trustworthy, understandable, assessable, and applicable health information, as well as communication via digital sources should be increased.
- » Improving Vaccination HL should have top priority, with a focus on judging vaccination information by improving the trustworthiness of information and communication on vaccinations.

## Regarding research on HL

- » The HL of the adult resident population should be measured regularly in as many countries as possible.
- » The next wave of measuring should be planned for data collection in 2024.
- » In preparation for this next wave, more specific research should be funded to analyze existing data in more depth as well as to revise, extend, and apply the tools for measuring HL and relevant correlates.
- » For the four specific HLs, more detailed analyses and publications on the HLS<sub>19</sub> data are needed as well as further research and development on improvements for later applications.
- » Additionally, further specific health literacies or relevant topics of General HL should be re-viewed, selected, and researched to be included in the next wave of measuring HLs.
- » More detailed analyses are needed regarding the costs and economics of HL.
- » Further dissemination of the results of the HLS<sub>19</sub> through peer-reviewed scientific publications is required.

The full report can be found at <https://m-pohl.net/Results>

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