CONCEPT NOTE

FOR A WHO ACTION NETWORK ON MEASURING POPULATION AND ORGANIZATIONAL HEALTH LITERACY (M-POHL NETWORK) WITHIN THE EUROPEAN HEALTH INFORMATION INITIATIVE (EHII)

1. INTRODUCTION

There is increasing evidence that health literacy contributes to effective choices of people with regard to health promotion, prevention and treatment of diseases, and that the decisions of more health-literate people accumulate to better health outcomes along the life course. But many people find it difficult to take adequate decisions for their health. This is not only a question of personal abilities, it is also a question of whether health systems provide easy-to-find, understandable, appraisable, actionable and target group-oriented information to their citizens in oral, written or audio-visual communication along the continuum from promoting health to treating disease. Many countries have already taken up to promote the health literacy of their citizens. To be able to systematically and effectively do so and to inform evidence-based policy and interventions, they need high-quality internationally comparative data which can help to determine which groups of the population need specific support, what the causes of these needs might be and which interventions seem most effective to address them, and not least to measure progress over time.

Amongst others, the Ministers of Health of the 5 German-Speaking European Countries (Quintet Countries) Austria, Germany, Liechtenstein, Luxemburg and Switzerland committed themselves to jointly strengthening their efforts on health literacy, to promote the institutionalization of a regular internationally comparative European survey on health literacy, and to support agenda-setting on health literacy by supra-national organizations like WHO-Euro.

Background

Health literacy is increasingly recognized as a determinant, mediator and moderator of health, and the first European health literacy survey (HLS-EU, 2009-2012 → compare appendix A for details) indicates that limited health literacy concerns large groups of the population in different countries. It is of specific concern that some groups of chronically ill people and older people – in other words, the population groups that need most healthcare interventions – have even lower health literacy than the general population average, and are therefore at higher risk of limited outcomes from the healthcare they receive. In order to get a better understanding of the overall situation and of specific areas for intervention (e.g. in relation to the health literacy of defined population groups or with regard to specific dimensions of health literacy) high-quality comparative data are needed on a regular basis. In addition to the 8 countries that participated in the HLS EU study, several more European countries have in the meantime recognized the importance of data collection on health literacy and have completed their own national surveys, using the comprehensive definition, model and tools developed for the HLS EU survey. But nation states, on their own, have only limited means of analysing and benchmarking the data they collect. For methodical reasons, uncoordinated national surveys are not apt for international comparison, even if they use the same survey tool. Thus, they can support evidence-based policy and practice only to a limited degree and do not allow necessary joint further development of the instruments for measuring health literacy. Since regular internationally comparative data allow identifying and tackling the causes of differences between countries and regions, such surveys create enormous added value.

Amongst others, the Ministers of Health of the 5 German-Speaking European Countries (Quintet Countries) Austria, Germany, Liechtenstein, Luxemburg and Switzerland discussed this issue in their annual meeting in 2016 and committed themselves to jointly instigating the institutionalization of a regular internationally comparative European survey on health literacy and to support agenda-setting on health literacy by supra-national organizations like WHO-Euro. In accordance with the results of a Health Literacy working group implemented by the Quintet countries, this paper outlines a proposal to start a WHO action network on measuring health literacy within the European Health Information Initiative (EHII), with the main aim to implement a regular European health literacy survey on the basis of broad and successively growing participation. Since in the meantime emerging evidence also suggests that health literacy-conscious structures and processes in healthcare systems and organizations are highly relevant determinants of clinical outcomes, it also recommends that the further development of instruments for measuring and comparing the health literacy-friendliness of healthcare systems and organizations should be a second aim of the proposed M-POHL network.

2. VISON, MISSION AND AIMS OF THE PROPOSED M-POHL NETWORK

It is the vision of M-POHL to enhance health literacy in Europe by ensuring the availability of high-quality and internationally comparative data to support political decisions and targeted practice interventions.

We suggest the M-POHL network to adopt an advanced understanding of health literacy as a relational concept. This perspective acknowledges that the level of health literacy a person has at his or her disposal in a given situation actually describes the fit of his / her personal competences with the demands these competences are confronted with in a given situation. In consequence, health literacy data need to be able to cover both personal skills and situational demands (in other words, the impact the health literacy friendliness of environments or organizational health literacy has on how people are able to access, understand, appraise and apply health-related information and services), and the fit between the two. Only such complex data will be sufficiently able to support decisions on where best to intervene in order to improve health literacy – by educating individuals and / or by developing more health literacy friendly situations, settings, organizations and systems.

Therefore, as overall aim of the M-POHL network this concept note suggests the M-POHL network takes action to support the availability of high-quality internationally comparative data on health literacy as a comprehensive and relational concept. This overall aim should be supported by the following goals:

1. The institutionalization of a regular, reliable, cross-national European health literacy survey, analogous to the HBSC[1] model (internationally coordinated and synchronized collection of data on population-based individual health literacy in as many countries in the European region as possible), including the identification of one or more European survey coordination centres with the aim to maintain and increase *the level of excellence* that is essential for comparative research.
2. To encourage the establishment of an international research consortium to support the survey coordination centre in recruiting participating countries, maintaining and continuously improving survey standards and quality, further developing the theoretical framework of the survey, the survey tool and methods, and the coordination of international data collection, analysis and reporting in line with commonly agreed standards.
3. The preparation of a task force on measuring organizational health literacy in participating countries, as originally proposed by the Institute Of Medicine (Brach et al. 2012), operationalized on a first European pilot basis by a Vienna team (Dietscher/Pelikan 2017), and followed

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[1] Health Behaviour in School-Aged Children Study

up in a working group of the WHO initiated international network of Health Promoting Hospitals and Health Services (HPH).
4. Joint reporting, disseminating and discussing health literacy results in Europe, including the provision of explanations for observed differences between countries and changes over time at first on the level of general and specific populations, but in the future it could also be aimed at measuring the health literacy-friendliness of organizations, settings and systems.
5. The development of a multi-level, international database on health literacy (covering both population and organizational health literacy).
6. The support of evidence-based policy making and practice in the field of health literacy by providing explanations and formulating recommendations and by encouraging international exchange of knowledge and experiences on national health literacy policies and practice of interventions, including advise for the WHO Regional Office for Europe on the development of concrete annual work plans for Health Literacy.
7. The recommendation of monitoring and evaluation strategies of implemented health literacy initiatives.
8. The stimulation of health literacy research in relevant areas by outlining needs for further research.

3. ROLES, RESPONSIBILITIES AND OPERATIONAL FRAMEWORK OF THE PROPOSED M-POHL NETWORK

In line with the generally recognized large-scale health challenges in the field of health literacy and the main aims of the proposed M-POHL network – to institutionalize a regular internationally comparative European health literacy survey of high quality and to support the collection of data also on organizational health literacy as prerequisites for evidence-based policy and practice on health literacy – M-POHL wants to encourage broad participation from countries in the whole WHO-European region.

The following terms of participation and cooperation are suggested:

Membership

1. The M-POHL network is composed of representatives of member countries, other EHII-connected networks and WHO-Euro (EHII).
2. The network must be able to draw on expert skills in policy-making and in research and survey design. Each member country is therefore represented by a **principal investigator** (senior researcher) and a **policy expert**.
    2.1. The **principle investigator / senior researcher** should have experience with population-based measurements, ideally with health literacy measurement, and be related to a research institution.
    2.2. The **policy expert** should be linked to or be part of the national health administration, and be able to impact on national decisions in relation to health literacy measurements and interventions.
3. Network membership will be assessed by the chair country in accordance with the M-POHL Core Group.
4. The work of all M-POHL network members will be **pro bono**, and costs that arise for example in relation with the attendance of meetings will have to be covered by the participants.
5. Any member may terminate their involvement in the M-POHL network by providing written notice to the chair country. In addition, the core group can decide to terminate participation of any member contradicting M-POHL rules and regulations.

Chair

6. M-POHL will have **a chair to guarantee smooth progress**. For the initial phase of M-POHL, **Austria** as one of the initiating countries is **willing to chair the network for an initial term of two years** (2018-2020).
7. **After that period**, the **chair will be elected by the M-POHL core group**. There is a possibility of renewal of the chair function for an additional two year term.
8. The **chair will inform the WHO Regional Office for Europe (EHII) on all strategic matters** pertaining to the M-POHL network. WHO-Euro will be consulted regarding any changes to the structure, modus operandi and/or content of the M-POHL network.
9. The chair has to represent a country with demonstrated experience in health literacy measurement and intervention.

Core group

10. The M-POHL core group consists of representatives of M-POHL members.
11. For an initial phase of 2 years, members of the M-POHL core group are from countries either involved in initiating the network, and / or represent a country with experience in the field.
12. After the initial phase, members of the core group will be elected by the M-POHL members.
13. There should not be more than 10 members of the core group.
14. The **core group will support the chair**. Specifically, chair and core group together will
    - 14.1. **draft the terms of reference of M-POHL**
    - 14.2. **propose project priorities and draft M-POHL action plans**
    - 14.3. **suggest a joint reporting and dissemination strategy**
    - 14.4. **prepare and invite network meetings,**
    - 14.5. **liaise with EHII and externally represent M-POHL**.

Decision-making

15. The M-POHL network is not a legal entity, and therefore cannot undertake any action without the explicit agreement in writing of each participating member country.
16. Network rules for decision making will be decided on in the first regular network meeting.

Relation to WHO-EURO’s EHII

17. The EHII group will function as an advisory board for M-POHL on the basis of technical exchange.
18. The chair and the members of the steering committee will **represent the M-POHL network** in different meetings of WHO-Euro and other organizations and institutions in the European health literacy arena.
19. The EHII chair has advisory status in M-POHL meetings.

Modus operandi of M-POHL

20. The M-POHL network will have **at least one face-to-face meeting annually**, and hold additional tele- or video conferences if needed. These meetings shall be organized by the chair country in collaboration with the core group.
21. For each meeting, there will be a **rapporteur**. This role will be **rotating between the network members**.

4. PRELIMINARY TIMELINE

- **August 2017**: Formal network announcement by WHO-EHII – beginning of nomination of network participants (national principle investigator and policy expert) by member states, and of identification of potential European survey coordination centres
- **November / December 2017**: First meeting – virtually or physically – of the network core group to prepare the Terms of Reference and next steps for 2018 and beyond
- **Early 2018**: Kick-Off-Meeting of the network – agreeing on the Terms of Reference and the next steps
- **2018**: Preparation of next European HL survey
    - Adaptation of survey tool and method by a group of scientists collaborating with the M-POHL network, to guarantee an internationally coordinated survey
    - National preparations of participation in the international survey by interested member states
- **2019**: First internationally coordinated survey (data collection)
- **2020**: Joint data analysis, reporting and dissemination

5. LIABILITY

Under no circumstances shall WHO assume any liability for acts carried out by M-POHL network members, regardless of whether such acts were carried out in the name of the M-POHL network or not. Furthermore, WHO in its sole discretion, may refrain from implementing any decision of the M-POHL Network if in the view of WHO, such decision gives rise to undue financial, legal or reputational liability or is contrary to WHO rules, regulations, administrative practices and programmatic and technical policies.

6. WHO NAME AND EMBLEM

Without the prior consent of WHO, no member shall, in any statement or material of an advertising or promotional nature, refer to its relationship with WHO or use the name and emblem of WHO.

APPENDIX A: THE FIRST EUROPEAN HEALTH LITERACY SURVEY – LIMITED HEALTH LITERACY IS A CHALLENGE IN SEVERAL EUROPEAN COUNTRIES

The “European Health Literacy project” took place from 2009 to 2012 and was supported and funded by the European Commission and national partners. A consortium of nine organizations[2] from eight EU member states (Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain) and 20 collaborating partners launched the first comparative European Health Literacy (HLS-EU) survey, which was one of the five goals[3] of the project.

In a first step, a systematic literature review of existing health literacy definitions and models was performed to develop an integrated definition of the concept as follows: ‘the knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life throughout the course of life” (Sorensen et al. 2012).

Based on this theory-driven definition, a multidimensional instrument to measure comprehensive health literacy in general populations – the HLS-EU-Q47 – was developed and validated (HLS-EU Consortium 2012; Sorensen et al. 2013). Besides the HLS-EU-Q47 and the Newest Vital Sign (NVS)-test – a test for functional health literacy – the complete questionnaire (the HLS-EU-Q86) includes a section on determinants and health consequences associated with health literacy.

Following a matrix formed by three domains of health – health promotion, disease prevention, and healthcare utilization – and four stages of health literacy, namely accessing, understanding, appraising, and applying information – the HLS-EU-Q47 includes 47 items on self-reported difficulties in these areas (Sorensen et al. 2013). Besides one general comprehensive health literacy index, the tool enables sub-indices for the three domains of health and for the four specific stages of health literacy, as well as 12 sub-sub-indices for combinations of these. Furthermore, four health literacy levels (inadequate, problematic, adequate, and excellent) were defined for the main indices. In addition, two short forms, the short-scale HLS-EU-Q16 and short-short scale HLS-EU-Q6, were developed.

On the basis of this tool, the first HLS-EU survey was conducted in eight EU member states. Data were collected by Computer Assisted Personal Interviewing (CAPI) or Paper Assisted Personal Interviewing (PAPI) in multistage random samples of about 1000 EU-citizens aged 15 years+ per country.

The HLS-EU survey reveals that limited (inadequate or problematic) health literacy is a challenge in all participating countries. Overall, nearly half of all adults across the eight participating countries reported limited health literacy skills[4]. The percentages of limited health literacy differed considerably between the participating countries; varying from 29 % in the Netherlands to 62% in Bulgaria. These results indicate that limited health literacy is a problem not only for particularly vulnerable groups, but also for the general population. Furthermore, a considerable social gradient for health literacy and considerable associations of health literacy with health relevant health indicators were demonstrated

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[2] Maastricht University (the Netherlands), National School of Public Health (Greece), University College of Dublin, National University of Ireland (co-sponsored by the Department of Health), Ludwig Boltzmann Institute Health Promotion Research (Austria, co-sponsored by Austrian Health Promotion Fund/Fonds Gesundes Österreich), Institute of Cardiology, Poland (co-sponsored by Ministry of Science/ Ministerstwo Nauki I Szkolnictwa Wyzszego), University of Murcia (Spain), Medical University (Sofia, Bulgaria); National Institute for Public Health and Environment (the Netherlands), NRW Centre for Health (Germany)

[3] The five HLS-EU project goals: (1) Adapt a model instrument for measuring health literacy in Europe; (2) Generate first-time data on health literacy in European countries, providing indicators for national and EU monitoring; (3) Make comparative assessment of health literacy in European countries; (4) Create National Advisory Bodies in countries participating in the survey and to document different valorization strategies following national structures and priorities; (5) Establish a European health literacy network.

[4] Respondents with limited health literacy skills reported difficulties with health literacy task, such as “*understanding what your doctor says to you*”, “*finding information on how to manage mental health problems such as stress or depression*”, or “*understanding information on food packaging, etc*. (health literacy tasks from the HLS-EU project).

by the study (HLS-EU Consortium 2012). The HL definition and results of the study were an important source for the WHO Solid Facts Health Literacy (Kickbusch et al. 2013).

The publication of the study inspired many research projects that followed the HLS-EU approach and methodology in the European region and beyond, especially in Asia.

In Europe, *population surveys* using the HLS-EU-instrument were conducted in Albania (Toçi et al. 2014), Belgium (Vandenbosch et al. 2016), the Czech Republic (Kučera et al. 2016), Denmark, Germany (Schaeffer et al. 2017), Hungary (Koltai/Kun 2016), Italy (Palumbo et al. 2016), Portugal (Espanha/Ávila 2016), and Switzerland (Bieri et al. 2016). Moreover, in a number of other countries, e.g. France, Norway and Russia, population surveys are in preparation.

A number of European countries also conducted health literacy studies in *specific populations* or *smaller research studies,* for instance the Austrian Immigrant Health Literacy Survey (Ganahl et al. 2016), the German health literacy of vulnerable Groups survey (Quenzel/Schaeffer 2016), the Swedish Health Literacy and Refugee's Experience of Health Examination Study (Wångdahl et al. 2015) or the CARLA study on the health literacy of older people in Eastern Germany (Tiller et al. 2015).

In Asia a coalition led by Taiwan started to coordinate a number of Asian countries (Indonesia, Kazakhstan, Malaysia, Myanmar, Taiwan and Vietnam) in using the translated HLS-EU-Q47 instrument in population surveys and started benchmarking data and results (Duong et al. 2015). In Japan a web-based survey following the HLS-EU approach was conducted (Nakayama et al. 2015).

The above-mentioned and quite a number of further studies demonstrate the growing acceptance of the concept of health literacy for public health in Europe and the attractiveness of the methodology of the HLS-EU study for measuring population health literacy. However, these activities have only slightly been connected, and opportunities for further joined development and expansion of instrument, shared learning and benchmarking have not been used. Therefore a structure to support a coordinated approach to measuring and improving health literacy data in the future at least in Europe should be established, to conduct "European Health Literacy Surveys at regular intervals through the continued support of the European Union, the WHO and countries", as recommended in WHO´s Solid facts on Health Literacy already in 2013.

Nevertheless, the availability of standardized comparative data which allowed benchmarking with other countries was and is very important to inform Austria's, Germany's or Switzerland´s health policy and practice. In order to know whether the efforts to improve the health literacy of the population which were triggered by the survey[5] are successful, it will be necessary to take the HLS-EU study as a baseline and do further comparative surveys for monitoring and evaluating policy and interventions. Ideally, this would be done in an internationally coordinated approach. Therefore, repeating the European HLS would be an important further step for these countries, and probably also for other ones.

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[5] Austria: Austrian Health Literacy platform, Austria's Health Target 3: to enhance the Health Literacy in the population, Germany: the National Health Literacy Action Plan, Switzerland: "e-Health-Strategy Switzerland" with Health Literacy a central, Health Literacy is a cornerstone of the National Strategy for Prevention of NCD (2017-2024), Swiss Alliance for Health Literacy and Competence

APPENDIX B: M-POHL STEERING COMMITTEE: FIRST SUGGESTION OF POTENTIAL MEMBERS

Each participating country should be represented in the M-POHL network by a researcher and a policy expert.

Country	Senior Researcher	Policy expert
Austria	Prof Jürgen M. Pelikan (University Vienna, Austrian Public Health Institution)	Dr Christina Dietscher (Ministry for Health and Women's Affairs)
Germany	Prof Doris Schaeffer (University of Bielefeld) (proposed)	t.b.d.
Luxemburg		
Switzerland	Prof Thomas Abel(University of Berne, Institute of Social and Preventive Medicine ISPM)	Karin Gasser (Federal Office of Public Health, Health Policy Directorate)

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