

### EHI Action Network on Measuring Population and Organizational Health Literacy (M-POHL)

#### Kick-off meeting – Minutes

February 22–23, 2018

Austrian Ministry of Health, 1030 Vienna, Radetzkystraße 2, Festsaal I



**PARTICIPANTS – M-POHL REPRESENTATIVES**

WHO		Claudia Stein	Division of Information, Evidence, Research & Innovation
AT	P	Christina Dietscher	Austrian Ministry of Labour, Social Affairs, Health and Consumer Protection
AT	R	Jürgen Pelikan	Austrian Public Health Institute
BE	R	Rana Charafeddine	Scientific Institute of Public Health
BE	R	Stephan Van den Broucke	Université Catholique de Louvain
BG	R	Antoniya Yanakieva	Medical University Sofia
CH	R	Thomas Abel	University of Bern
CH	P	Karin Gasser	Federal Office of Public Health
CZ	R	Zdeněk Kucera	Czech Health Literacy Institute
CZ	P	Petr Struk	Ministry of Health
DE	R	Doris Schaeffer	University of Bielefeld
DE	P	Alexander Schmidt-Gernig	Ministry of Health
DE	R	Dominique Vogt	Hertie School of Governance
EL	R	Christos Lionis	University of Crete
EL	P	Elena Petelos	University of Crete
ES	R	Maria Falcon Romero	University of Murcia
ES	P	José Carlos Vicente López	Regional Government of Murcia
IE	R	Gerardine Doyle	University College Dublin
IE	P	Sarah Gibney	Department of Health
IL	R	Diane Levin	Clalit
IT	R	Paola de Castro	Istituto Superiore di Sanità
IT	R	Simona Giampaoli	Istituto Superiore di Sanità
LU	P	Anne Calteux	Ministry of Health
LU	P	Caroline Verhoeven	Ministry of Health
NL	R	Jany Rademakers	NIVEL
NO	P	Christopher Le	Norwegian Directorate of Health
NO	R	Kjell Sverre Pettersen	Oslo and Akershus University College of Applied Sciences
PT	P	Miguel Telo de Arriaga	Ministry of Health
RU	P	Oxana Drapkina	Russian academy of science
RU	R	Maria Lopatina	National Medical Research Center for Preventive Medicine
SE	R	Josefin Wangdahl	University of Uppsala
TR	R	Pinar Okayay	Adnan Menderes University
UK	R	Gillian Rowlands	University of Newcastle

**INTERNATIONAL GUESTS**

OECD		Liliane Moreira	OECD Paris
HBSC		Joanna Inchley	University of Saint Andrews

**FURTHER PARTICIPANTS OF HOST COUNTRY**

AT	R	Julia Bobek	Austrian Public Health Institute
AT	P	Anna Fox	Austrian Ministry of Labour, Social Affairs, Health and Consumer Protection
AT	R	Peter Nowak	Austrian Public Health Institute
AT	P	Stefan Spitzbart	Main association of Austrian Social Security Institutions
AT	P	Kristina Walter	Public Health Fund Styria

## 1 Agenda of the kick-off meeting

<b>February 23, 2018</b>	
09.00–09.30	<b>Opening and Welcome</b> <ul style="list-style-type: none"> <li>• Welcome address (<i>Christina Dietscher, MoH</i>)</li> <li>• Opening remarks by representatives of “Quintet Countries” (<i>Anne Calteux, Luxemburg; Karin Gasser, Switzerland; Alexander Schmidt-Gernig, Germany</i>)</li> <li>• Introduction and Opening Remarks (<i>Claudia Stein, WHO-Euro</i>)</li> </ul>
09.30–10.00	<b>Tour de Table</b>
10.00–11.00	<b>Constitution of the Action Network on Measuring Health Literacy</b> <ul style="list-style-type: none"> <li>• HBSC as a role model for the organization of the HL survey (<i>Jo Inchley, University of St. Andrews</i>)</li> <li>• Introduction to the Action Network – TORs and Modus Operandi (<i>Christina Dietscher, MoH; Jürgen Pelikan, University of Vienna, GÖG</i>)</li> </ul>
11.00–11.30	Coffee break
11.30–12.30	<b>Overview on developments in health literacy</b> <ul style="list-style-type: none"> <li>• Health literacy definitions, measurements and strategies: experiences from OECD countries – preliminary findings (<i>Liliane Moreira, OECD</i>)</li> <li>• The evidence on existing policies and their effectiveness for improving health literacy: Preliminary findings from the WHO/Europe’s Health Evidence Network (HEN) synthesis report (<i>Gill Rowlands, University of Newcastle</i>)</li> </ul>
12.30–13.30	Lunch break
13.30–14.30	<b>Introduction to group work: Tasks of the science and policy groups of the action network</b> <ul style="list-style-type: none"> <li>• Experiences and lessons learned from the Health Literacy Survey 2011 (<i>Jürgen Pelikan, University of Vienna, GÖG</i>)</li> <li>• What does health policy need from a next HL survey, and how can policy support the survey? (<i>Christina Dietscher, MoH</i>)</li> </ul>
14.30–15.30	<b>Group Work I</b>
15.30–16.00	Coffee break
16.00–17.30	<b>Group Work II</b>
17.30–18.00	<b>Reports from the groups</b>
<b>February 24, 2018</b>	
09.00–10.00	Recap: Solved, open and new questions <ul style="list-style-type: none"> <li>• Scientific group: Methodological aspects: refinement of the instrument and of the survey design</li> <li>• Policy group: Political commitment towards HL, expectations to and financing of the survey</li> </ul>
10.00 –11.00	Group work (continued)
11.00–11.30	Coffee break
11:30–13.00	Group work (continued)
13.00–14.00	Lunch break

14.00–16.00 **Wrap-Up of interim results**

- Presentations from the groups
  - Next steps (*Christina Dietscher, MoH; Jürgen Pelikan, GÖG*)
  - Closing remarks (*Claudia Stein, WHO-Euro*)
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Slides of meeting presentations were already sent to participants prior to the minutes.

## 2 Plenary agreements and further discussion points

### 2.1 The Concept Note as basis for cooperation in M-POHL

**Agreement:** National representatives agreed that the “**Concept Note**” that was distributed before the meeting, is the **basis of the cooperation within M-POHL**.

### 2.2 Tasks of M-POHL and scope of the kickoff meeting

**Agreement:** M-POHL has two foci: one on **population health literacy**, one on **organizational /settings / systems health literacy**. Because of time pressure in some member states, tasks in relation to population health literacy will be taken on first.

- » The kick-off meeting focused on agreements and discussion points in relation to relevant next steps for preparing the next European population-based health literacy survey.

### 2.3 International M-POHL steering core group

**Agreement:** National representatives agreed that the international **steering core group should take the responsibility for interlinking the policy and research perspectives** in the network in order to facilitate smooth progress.

- » For the initiating phase, the steering core group will consist of representatives of the initiating countries Austria, Germany, Luxemburg and Switzerland, and is co-chaired by Christina Dietscher and Jürgen Pelikan, Austria (“international coordinators”).

### 2.4 National representatives in the international M-POHL network

**Agreement:** Each member state of the M-POHL network should appoint **two representatives, one for the policy and one for the research perspective**.

### 2.5 National steering groups

**Agreement:** The national representatives will jointly initiate / install **national steering groups consisting of representatives of policy, research and citizens for the working period 2018–2020**.

- » The international coordinators already circulated criteria for setting up national steering groups and their suggested tasks (cf. Homework).
- » The national representatives in M-POHL should be ideally also the chairs of the national steering group.

## 2.6 Calculation tool for survey costs

**Agreement:** The international coordinators should provide all national representatives with a **tool to calculate approximate national costs** of the next health literacy survey (cf. Homework).

- » A revised version of the tool presented during the meeting was already circulated after the meeting (cf. Homework).

## 2.7 Communication platform

**Agreement:** The international coordinators will provide a proposal **for an M-POHL e-communication platform**.

Further discussion:

- » The Austrian Public Health Institute suggested hosting an online platform on their server, which provides a high level of data security.
- » Alternatively suggestions included an integration into the existing EHII-Platform hosted by the European Commission, and the investigation of possibilities to set up a share point.

## 2.8 European survey coordination center(s)

**Agreement:** A decision on the **European survey coordination center** should be taken at the **August meeting**.

- » Terms of reference for the coordination center will be specified by the international coordinators and circulated in spring (cf. 2.12 Homework).

## 2.9 Next meeting

**Agreement:** The **next meeting will take place in Bern (CH) in August 2018**.

- » The date was already fixed for **August 27<sup>th</sup>–28<sup>th</sup>** via a doodle poll.

## 2.10 Joint M-POHL statement

**Agreement:** A **joint Vienna Statement** of M-POHL **should be issued**.

Further discussion:

- » The objectives of the statement are to share joint messages, to increase visibility and to strengthen the mandate of the M-POHL network and its national representatives.
- » Based on a first draft by Elena Petelos, Claudia Stein (WHO Euro) prepared a draft statement, which was circulated among those present at the meeting and adapted according to feedback.
- » The edited version of the statement is attached to the minutes.
- » The "Vienna Statement" can be used by all members of M-POHL to support the preparation, implementation and dissemination of M-POHL nationally and internationally.

## 2.11 Presence at the WHO-Euro RC meeting 2018

**Agreement:** M-POHL should try to be represented on the **agenda of the next session of WHO Regional Committee for Europe** in form of a **technical briefing**.

## Further discussion:

- » Strategies for raising “the issue” (M-POHL) at the next regional committee session taking place in Rome from 17<sup>th</sup> to 20<sup>th</sup> September 2018 were discussed. These included awareness-raising by members of the standing committee who will have their next meetings in March and May 2018.

## 2.12 Homework

**International coordinators** are asked to:

- ✓ circulate the criteria for setting up national steering groups and their suggested tasks.
- ✓ circulate the calculation tool by which national representatives shall calculate approximate national costs.
- ✓ edit and finalize the M-POHL “Vienna Statement” based on Claudia Stein’s draft and the feedback of representatives in accordance with the core group.
- ✓ do a doodle poll to fix the date of the next M-POHL meeting in Bern (CH) in August 2018.
- » draft specifications of terms of reference for the European survey coordination center.
- » make efforts to put M-POHL on the agenda of the next session of WHO Regional Committee for Europe.
- » establish a sub-group on communication and visibility with the representatives of the Czech Republic and of Greece

**National representatives** are asked to

- » establish a national M-POHL steering group
- » estimate national survey costs by using the calculation tool and feed cost estimates into budgetary negotiations according to national schedule.
- » provide feedback on open international research questions to international coordinators by April 25
- » start preparations for national survey according to the specified national tasks
- » share Vienna Statement with national M-POHL representatives and stakeholders
- » if possible, support international agenda-setting in relation to preparing M-POHL presence during the Rome RC meeting
- » seek national statistical advice on sampling and sample size. (How many people need to be included to ensure representativeness for age, gender, region, etc.?)
- » collect information on different methods of data collection in their member state. (What method(s) for data collection are used per member state? What are the experiences of comparable surveys?)
- » indicate in which (research) working group they would like to take part, either as contributors or in a leading function

✓ = already done; » = to be done

## 3 Working groups during the meeting

For this meeting, the participants worked partly in groups, one focusing primarily on research, the other on policy questions.

### 3.1 Policy perspective

The group that focused on the policy perspective mainly discussed expectations towards a next international HL survey and open questions in relation to preparing participation in the next survey on national level.

#### 3.1.1 Benefits of an internationally coordinated survey

**Discussion:** Participants raised the following arguments in favor of an internationally coordinated survey, as compared to a survey on national level alone. An internationally coordinated survey...

- » is cost-effective in relation to development of survey tool, research protocol, joint usage of translations into different languages, etc.
- » allows international / regional comparisons
- » enables the development of joint hypotheses to explain survey outcomes, the development of joint recommendations and the sharing of good practices
- » helps to increase significance of topic, process and results nationally and internationally
- » helps to keep energy and motivation high.

#### 3.1.2 Questions for research that are of interest to policy

**Discussion:**

- » How can trends / change / progress be shown?
- » How can comparability be ensured?
- » What is the timeline of the research?
- » Which human resources will the research require?

#### 3.1.3 Policy priorities on topics and target groups

**National representatives collected main policy priority topics relating to health literacy and discussed specific target groups that are of particular relevance in the respective member states. These form a relevant background for the research perspective to select optional packages for the next HL survey.**

**Policy priorities:**

- » NCD influence factors, incl. nutrition, BMI / obesity, smoking, alcohol consumption, care / self-management (Russia, Greece, Portugal, Luxemburg, Norway, Austria, Switzerland, Ireland, Czech Republic)
- » Primary Health Care (Russia, Greece, Austria, Luxemburg, Norway, Ireland, Czech Republic)
- » Health system navigation (Luxemburg, Switzerland, Ireland, Portugal)
- » Health Technology Assessment (Greece)
- » Migrant health, esp. maternal care and mental health (Greece, Switzerland)
- » Vaccination / adult immunization (Greece, Luxemburg, Norway, Ireland, Czech Republic)
- » eHealth / digital health literacy, incl. patients and professionals (Czech Republic, Portugal, Luxemburg, Norway, Austria, Switzerland, Ireland, Germany, OECD)
- » Mental health, esp. dementia (Greece, Portugal, Norway, Switzerland, Ireland, Czech Republic, Luxemburg)

- » Accident prevention, esp. falls and traffic accidents (Greece, Portugal, Norway)
- » Elderly care (Portugal, Norway, Switzerland, Ireland, Luxemburg)
- » AMR / antibiotics (Norway, Luxemburg, OECD)
- » Communication in health care / shared decision making (Austria, Ireland, Germany, Portugal, Luxemburg)
- » Written health information (Austria, Germany)
- » Health care costs, incl. access to medicines (Luxemburg, Norway, Switzerland, Ireland, Czech Republic, Portugal)
- » Vulnerable groups, e.g. the elderly, people with low socioeconomic status (Norway, Switzerland, Ireland, Portugal, Germany)
- » Health education (Germany)
- » Breast feeding (Ireland)

### Target groups

- » Men (25–60 years old), esp. concerning mental health and obesity (Russia)
- » Young women (15–30 years old), esp. concerning maternal care and smoking (Russia)
- » Youngsters / adolescents (Russia)
- » Elderly people (50+) → should be oversampled (Russia, Ireland, Switzerland)
- » Health care providers, esp. in relation to vaccination (Greece, Luxemburg, Ireland, Portugal)
- » Travelers (Ireland)
- » Informal care givers (Ireland)
- » Migrants, esp. mothers and NCD-sufferers → implications for necessary language skills / questionnaire translations for data collection (Norway, Germany)
- » Sufferers from NCDs e.g. diabetes / (multiple) chronic diseases
- » Urban vs. rural populations

### Further discussion:

- » A matrix of topics/survey questions and target groups was suggested as different topics and questions are relevant for different age groups (15–29, 30–70, 71+)

## 3.1.4 Survey scale and sample size for the next survey

### Discussion:

- » **Interests of member states in relation to national or regional representativeness of the next survey vary.** Some might only be able to perform the survey in pilot regions (e.g. Russia), others would be interested in language regions (e.g. Switzerland) and some countries are interested in analyzing urban vs. rural regions (Germany).
- » Overall, **there is a high expectation to get more information on options and scenarios from the research perspective.**

## 3.1.5 Expectations towards data collection

### Discussion:

- » There was a **preference for online or telephone interviews** as compared to face-to-face interviews, **if this means that sample sizes could be enlarged.**
- » Overall, more guidance on this topic was expected from the research perspective on national and international level.

### 3.1.6 Survey financing – timeline for national budget negotiations

**Agreement:** Each country will use the calculation tool provided by the international coordinators to estimate national survey costs, and will feed the estimate into the budgetary negotiations, according to national deadlines. Survey costs will become more precise in the progress of survey preparations, but the calculation tool should allow all countries to at least reserve a reasonable amount of money in due time.

### 3.1.7 National structures and strategies in support of HL

**Discussion:** Member state's structures and strategies in support of HL vary from national action plans and institutes to a rather loose link to existing national priorities, strategies and structures. These existing national structures and strategies should be used to support an efficient implementation of the survey and HL measures.

- » The Czech Republic has an institute of health literacy that host both a research and a policy line.
- » The Luxemburg health conference 2017 focused on health literacy and the topic will feature in the next national health program. There are also efforts to mainstream HL.
- » Portugal holds a national strategy group involving a broad range of stakeholders.
- » Norway is in the process of establishing a national group on HL, probable interlinked with a larger Nordic group.
- » Switzerland has a Health Literacy Alliance.
- » Austria has a national platform on health literacy (ÖPGK) that will host the national M-POHL group.
- » A regional task force for Crete is in place in Greece.
- » Germany has a national action plan and an expert committee on HL.
- » Ireland has a national health literacy advisory panel. HL could be included in the next "Health Ireland Framework".

### 3.1.8 National and international visibility of M-POHL

**Agreement:** Participants decided on the formulation of a **joint M-POHL Vienna Statement to be used nationally and internationally** to promote M-POHL, and on the formation of a **sub group on communication and visibility** that should also support the visibility of M-POHL on international level (such as WHO meetings).

Further discussion:

- » Elene Petelos (GR) and Petr Struk (CZ) were prepared to join the sub group.
- » Petr Struk suggested and attempt to promote M-POHL at the Seventy-first World Health Assembly (21-26 May 2018, Geneva)

### 3.2 Research perspective

#### 3.2.1 Objectives of study / research questions

**Agreement:** Besides monitoring of HL, **specific (new) research questions** should be developed for the study!

Within the discussion evolved some common understanding that it would be wise to use the following matrix (see Table 1) for orientation to better understand the tasks and options for the study protocol.

- » The content of the questionnaire follows the generic model of HL: Determinants → HL measure → consequences (correlates of HL).
- » Levels of obligation follow the example of HBSC: mandatory core, optional add-on packages, national add-ons / specificities.

**Table 1: Matrix on study content and design by level of obligation**

	Study content			Study design		
	Determinants	HL Measures	Consequences	Population	Sample size	Data collection
<b>Mandatory core</b>	???	Q16	???	Residents 18+	For "larger" countries* min. 1.000	???
<b>Optional add-on packages</b>	???	Q47	???	???	???	???
<b>National add-ons</b>	???	???	???	???	???	???

??? = To be further determined in working group(s) (WG(s))

\* ≥ 1 Mio. inhabitants

**Agreement:** National representatives should **strive for consensus also for optional add-on packages** to insure international comparability at least between some member states, but **not for national add-ons!**

#### 3.2.2 Instrument

**Agreement:** on a **perception based / self-reported mandatory core measure for HL:** the HLS-EU Q16, but optional HLS-EU-Q47 (probably DE, CZ) and **optional additional performance based test**

- » By using the short form there is place for including optionally measures for specific aspects of HL, like digital HL, mental HL etc.

Further discussion:

- » **As possible additional measures** were discussed the topics of health economics, social network distribution, eHealth, mental health. Measures such as those related to health behavior (e.g. tobacco) could be skipped, which would give more space for new measures.
- » Using a **mixed methods approach** could get a deeper understanding of the complexities of health literacy, but not to test the instrument.
- » The **standardization of translations** into different languages needs to be considered.

### 3.2.3 Population

**Agreement: Residents** (instead of EU-citizens) in member states, **aged 18+** (instead of 15+), since there are legal difficulties to interview minors in some countries.

### 3.2.4 Sampling

**Agreement:** to have a **probability sampling**

**Agreement:** to have national samples as much as possible representative for a number of criteria (national level, regions, migrants, etc.), depending on information from national statisticians and possibilities of funding (cf. 2.12 Homework)

- » Sample size therefore may differ and depend on the size of the member states, but there should be a minimum of 1.000 for "larger" countries ( $\geq 1$  Mio. inhabitants).

### 3.2.5 Data collection

**Agreement: Personal interviews would be the "gold standard", but telephone interviews or internet based data collection respectively a mixed method strategy (e.g. stratified by age: e.g. 18–30 internet based, 31–60 telephone, 61+ personal) for data collection) should be considered to guarantee financial feasibility.**

- » Therefore, **national data collection routines should be taken into account** (cf. 2.12 Homework). But the risk of producing non-comparable results has to be considered also.

Further discussion:

- » For Online: acoustically played questions, option to choose language on front page
- » Introducing the questionnaire by a short explanation of the survey to reduce the selection bias.
- » The General Data Protection Regulation (GDPR), which comes into force on 25 May 2018, needs to be considered.

### 3.2.6 Working groups

**Primarily based on the matrix (see above) the following working groups were considered (Table 2).**

- » National representatives are asked to indicate in which working group they would like to take part, either as contributors or in a leading function (cf. 2.12 Homework).
- » Some national representatives already offered to volunteer in working groups, but now all are invited to choose for which aspects they specifically are willing to support the drafting of the study protocol!

Table 2: Overview of working groups to be installed

Working (sub-)group	Topics	Representatives
Working group 1	Measuring Health literacy	Jürgen AT, Zdeněk, CZ; Stephan, BE;
Working group 1.1	Core module Slight improvement of HL Q16 (also for export into other studies)	Maria ES; Dominique, DE; <u>Jürgen, AT</u>
Working group 1.2	<b>Optional modules / aspects of HL</b>	
	– Digitalization	Sverre, NO; Claudia WHO

	– Migration	Josefine, SE
	– Healthcare HL	
<b>Working group 2</b> <i>(could be a mixed group of policy and research)</i>	<b>Determinants/indicators for disaggregation</b>	Simona, IT
	– Migration	
	– Urban/rural	
	– Classic indicators (age, income, education, etc.)	
<b>Working group 3</b> <i>(could be a mixed group of policy and research)</i>	<b>Consequences</b>	Gerardine, IE; Jany, NL; Doris and Dominique, DE; Josefin, SE; Gill, UK; Antoniya, BG
	– Healthcare & social costs	
	– Chronic conditions (specific ones)	
	– Health behavior/health risks/information behavior	
	– Navigation of healthcare	
<b>Working group 4</b>	<b>Data collection (technical dimension)</b>	Rana, BE
	– Sampling	
	– Methods for data collection	
	– Finding external institutions for data collection (criteria, identifying, tender, collaboration, provision of training on the topic)	
<b>Working group 5</b>	<b>Methodology (creative dimension)</b>	
	– Qualitative and quantitative methods	Gerardine, IE; Claudia WHO; Maria, ES

Results of working groups 1–5 will be synthesized in the study protocol.

### 3.2.6 Suggestions for questions to be discussed in the Working Groups

Generally, WGs should also take relevant results of the policy perspective into consideration (see above)!

WG1:

- » Formulate research questions for developing further HL (core) measurement and new optional measurements for specific aspects of HL.
- » Find fitting existing instruments.
- » Propose a procedure for developing new measures.

WG2:

- » Formulate research questions for determinants (disaggregation)!
- » Then evaluate respective indicators included in the HLS-EU-Q86.
- » Propose which indicators have to be kept, which have to be eliminated and which new ones should be added.

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- » Propose detailed measures (international standard measures for best comparability) for all indicators!

### WG3:

- » Formulate research questions for consequences of HL!
- » Then evaluate respective indicators included in the HLS-EU-Q86.
- » Propose which indicators have to be kept, which have to be eliminated and which new ones should be added, especially for proposed new topics.
- » Propose detailed measures for all indicators!
- » WG4:
- » Should start with the methods of the HLS-EU study and propose what should be taken and what be changed and further developed!

### WG5:

- » Should make creative propositions on how to complement or improve the standardized, quantitative survey by qualitative accompanying research!