HLS•EU

Executive Agency for Health and Consumers

LAUNCH OF THE EUROPEAN HEALTH LITERACY SURVEY!

22-23 November 2011

WWW.HEALTH-LITERACY.EU

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www.health-literacy.eu

MSD

Brussels 22. November 2011

Dear conference guest

On behalf of our co-hosts, members of the European Parliament, Mr. Christofer Fjellner, Mrs. Karin Kadenbach and Mr. Pat the Cope Gallagher and the consortium of the European Health Literacy Project it is a pleasure to welcome you to the European Health Literacy Conference in Brussels at the Museum of Natural Sciences.

The registration was closed due to overwhelming interest and we are proud to announce that we have reached a maximum of 175 participants from more than 15 countries and a broad range of European and national institutes and organizations.

The aim of the conference is to launch the results of the European Health Literacy Survey conducted under the European Health Literacy Project (HLS-EU) and to discuss the implications as well as defining solutions for the future. The study shows that on average nearly 46% of the respondents in the survey possess limited health literacy; it is thus a general health problem, and it needs to be tackled since inadequate and problematic levels of health literacy create unnecessary and expensive barriers and challenges for the citizens as well as for the European societies.

We are delighted that you are here to take actively part in the discussions and we look forward to our distinguished speakers to lead the way when they during the two days will assess health literacy from different perspectives such as patients as co-producers of health, inequities in health, long life learning and productivity, learnings from the international experiences and national best practices.

Enjoy the conference!

H. Brand

Professor Helmut Brand
The European Health Literacy Project (HLS-EU)
Maastricht University

Content

1. Program

22nd November 2011

09.30-10.00	Registration
	Facilitator: Leo Cendrowicz, Brussels correspondent of the Time Magazine
10.00-10.30	Opening Welcome by MEP Christofer Fjellner, EPP, Sweden Key Note Speech by John Dalli, European Commissioner for health and Consumers
10.30-10.50	Health Literacy and the HLS-EU – What is it all about? Prof. Ilona Kickbusch, Geneva Graduate Institute, Switzerland
10.50-11.20	The State of Play of Health Literacy – Main findings of the first Health Literacy Survey in Europe Prof. Jürgen Pelikan, Ludwig Boltzmann Institute, Austria
11.20-12.20	Panel I: Health Literacy as a key competence – to tackle health inequalities through e-health • Zoran Stancic, Deputy Director-General, DG Information and Society • David Boyd, Director European Government and Public Policy, GE Healthcare • MEP Karin Kadenbach, S&D, Austria, co-host • MEP Antonyia Parvanova, ALDE, Bulgaria • Nicola Bedlington, Director, European Patients' Forum
12.20-13.30	Lunch
13.30-14.30	Panel II: Health literacy to navigate the system – patients as co-producers • Andrzej Rys, Director of Public Health, DG Health and Consumers • Stanimir Hasurdjiev, Executive Director, European Liver Patients Association • Tania Weng-Bornholt, Stakeholder Manager Patients/External affairs, MSD • MEP Christofer Fjellner, EPP, Sweden • Dr Michael Wilks, CPME Past-President, The Standing Committee of European Doctors • Elena Bonfiglioli, Senior Director Health Industry Europe Middle East and Africa, Microsoft
14.30-15.30	Panel III: Health Literacy as a cornerstone – to boost growth and productivity in the EU through life-long learning • Maria Iglesia Gomez, Head of Unit 01 "Strategy and Analysis", DG Health and Consumers • Bart van de Waetere, EU Affairs Manager, Nestlé • Hildrun Sundseth, Director, European Institute for Women's Health • Stefan Crets, CEO, CSR Europe • Nolwenn BERTRAND, European Affairs Developer, Edenred
15.30-16.00	Break
16.00-16.15	Health Literacy 2020 – Recommendations for policy makers MEP Christofer Fjellner, EPP, Sweden
16.15-16.30	Concluding remarks: Health Literacy – A visionary Outlook Professor Helmut Brand, Maastricht University, the HLS-EU Project
16.30-17.00	Reception

23rd November 2011

	Facilitator: Professor Don Nutbeam, Vice-Chancellor, University of South Hampton, UK
09.00-09.30	Welcome and introduction to the day Professor Helmut Brand, Maastricht University, HLS-EU Project Opening by MEP Pat the Cope Gallagher, ALDE, Ireland
09.30-10.15	Panel IV: Implementing health literacy policies across the world • The American perspective, Dr. Arthur Culbert, Trustee, Saint Luis College of Pharmacy, Saint Louis, Missouri • The Asian-Pacific perspective, Prof. Richard Osborne, Deakin University, Australia • The WHO perspective (Agis Tsouros, WHO Europe) (invited)
10.15-11.00	Panel V: Health literacy policy developments in Member States – show cases • The Dutch Health Literacy Alliance, Director Jaap Koot, National Institute of Health Promotion • Health Literacy initiatives in Ireland, Dr. Gerardine Doyle, University College Dublin and Sarah O'Brien, Health Service Executive Brief introduction to the show cases followed by moderated discussion including more countries in the panel from the HLS-EU Project
11.00-11.30	Break
11.30-12.30	Panel VI: Health Literacy – how to make it happen in the EU? • The HLS-EU consortium: Professor Demosthenes Agrafiotis, Greece • Professor Richard Osborne, Australia • Diretor Jaap Koot, the Netherlands • MEP Karin Kadenbach, Austria • MEP Pat the Cope Gallagher, Ireland • MEP Christofer Fjellner, Sweden • MEP Martin Kastler , Germany
12.30-12.45	Presentations of recommendations and concluding remarks Professor Helmut Brand, Maastricht University, the HLS-EU Project
12.45-14.00	Lunch

2. **List of speakers and facilitators**

Facilitators

Journalist Leo Cendrowicz, Brussels correspondent of the Time Magazine
Professor Don Nutbeam, Vice-Chancellor, University of South Hampton, UK

European Commission

Andrzej Rys, Director of Public Health, DG Health and Consumers
John Dalli, European Commissioner for Health and Consumers
Maria Iglesia Gomez, Head of Unit 01 "Strategy and Analysis", DG Health and Consumers Zoran Stancic, Deputy Director-General, DG Information and Society

European Parliament

Antonyia Parvanova, ALDE, Bulgaria
Christofer Fjellner, EPP, Sweden
Karin Kadenbach, S&D, Austria
Martin Kastler , Germany
Pat the Cope Gallagher, ALDE, Ireland

WHO Europe

Dr. Agis Tsouros, WHO Europe

Research institutes and universities

Dr. Arthur Culbert, Trustee, Saint Luis College of Pharmacy, Saint Louis, Missouri
Professor Demosthenes Agrafiotis, Greece
Dr. Gerardine Doyle, University College Dublin
Prof. Helmut Brand, Maastricht University, the Netherlands
Prof. Ilona Kickbusch, Geneva Graduate Institute, Switzerland
Prof. Jürgen Pelikan, Ludwig Boltzmann Institute, Austria
Prof. Richard Osborne, Deakin University, Australia

Public Institutions

Jaap Koot, Director, National Institute of Health Promotion
Sarah O'Brien, Health Service Executive

Non-governmental organizations

Hildrun Sundseth, Director, European Institute for Women's Health
Nicola Bedlington, Director, European Patients' Forum
Stanimir Hasurdjiev, Executive Director, European Liver Patients Association
Stefan Crets, CEO, CSR Europe

Private sector

Bart van de Waetere, EU Affairs Manager, Nestlé
David Boyd, Director, European Government and Public Policy, GE Healthcare
Elena Bonfiglioli, Senior Director Health Industry Europe Middle East and Africa, Microsoft
Nolwenn Bertrand, European Affairs Developer (Edenred)
Tania Weng-Bornholt, Stakeholder Manager Patients/External affairs, MSD

3. MSD as conference partner

MSD is committed to Health Literacy
As a healthcare company MSD is committed to partnering with a wide range of stakeholders and supports projects that empower people to make informed health decisions. We demonstrate our commitment to increasing access to healthcare through far-reaching policies, programs and partnerships across all our markets. For more information, visit www.msd.com.

Health Literacy – What MSD Does
The European Health Literacy Conference organized by the Maastricht University was partly made possible by the support of MSD. MSD's subsidiaries in Austria, Germany, Ireland, Spain, Switzerland and the US have partnered with various agencies and foundations in support of scientific research and health literacy programs.

MSD in Switzerland supported the first health literacy survey in Europe, conducted by the University of Zurich amongst the Swiss population. Health Promotion Switzerland, the Swiss Medical Association, Public Health Switzerland, MSD in Switzerland and the Careum Foundation built up a health literacy alliance which includes a variety of stakeholders. The enhancement of health literacy also has a place in the draft of the prevention law currently being discussed in the Swiss Parliament.

MSD in Ireland introduced the Health Literacy initiative in autumn 2007 with the launch of the Crystal Clear MSD Health Literacy Awards. The aim of the awards is to recognise those people or organisations working in the healthcare arena that are making efforts to communicate more clearly with patients. The MSD/NALA Health Literacy Initiative established political contact in Ireland, leading the country to be included in the EU Health Literacy Survey. The Irish Government is also considering establishing Government Policy in the area of Health Literacy.

In addition to the research conducted in the framework of the European Health Literacy Survey *MSD in Austria* supported further research of the Ludwig Boltzmann Institute to allow for regional analysis of health literacy in the Austrian population.

In order to help people better understand patient information leaflets *MSD in Germany*, together with several patient and older people organisations launched a project to revise the leaflets of MSD products. In addition, audio versions of patient leaflets have been created so that this information is also accessible for blind people. *MSD in Spain* partnered with the Josep Laporte Library Foundation, and the University Autónoma de Barcelona on the development of a program on e-health literacy, the "University of the Patients" website.

In parallel to European activities and in an effort to standardize health communications consistent with health literacy principles, the *Merck Global Human Health US Market* established criteria by which patient education resources will be created and evaluated. In 2010, Merck Global Human Health US Market partnered with Health Literacy Missouri to rewrite diabetes patient education material thus ensuring the implementation of health literacy principles.

4. The venue – Museum of Natural Science

The European Health Literacy Conference takes place in the Museum of Natural Science in Brussels. The museum has Europe's largest dinosaur gallery, which emphasizes science and authenticity. It includes the famous iguanodons of Bernissart and lots of new dinosaur skeletons and casts as well as interactive exhibits and an on-site paleontology and geology laboratory for children. The Museum acts as a showcase for scientific research conducted by the Royal Belgian Institute of Natural Sciences, an internationally renowned center of which the Museum is an integral part.

250 years of science

About 250 years ago the then governor of the Netherlands, Karel van Lotharingen, established a cabinet of curiosities. Wealthy enthusiasts were very keen on building up collections of artefacts at that epoch. After his death, the collection ended up in a roundabout fashion in the hands of the City of Brussels. Finally, it was placed in the Natural History Museum, in 1846, where the collection continued to grow: it now features 37 million specimens! This natural science collection and the research surrounding it form the basis of the Museum of Natural Sciences. What you see in the Museum is only the tip of a gigantic iceberg! You can marvel at the most splendid items in the permanent exhibition rooms and now in the new 250 years of Natural Sciences exhibition as well.

Did you know there used to be a zoo in the Leopold Park behind the Museum? And that after it died, in 1880, the elephant kept in the zoo was stuffed and is now on display in this room? Other showpieces are the whales that were excavated during work on the Antwerp fortress belt. With a nod to the iguanodons close by, you will discover here a picture showing the ingenious process for assembling the first iguanodon skeleton. You will become acquainted with the oldest collection of Russian minerals, with the unique Ishango bone (*) or with the fossil remains from Messel. You can stroll along besides a superb stuffed specimen of a thylacine, a species that is now extinct. You can browse through the log books, manuscripts and sketches of the Institute's scientists who sailed to the South Pole on board the Belgica in 1897. You can see two gorillas from the Congolese National Parks, which the Institute founded in about 1930, with the support of the Royal House. Even more recent items are the stuffed tiger and giant tortoise, as an illustration of CITES (Convention on International Trade in Endangered Species of Wild Fauna and Flora) and the petrified forest of Hoegaarden brought to the surface during work on the high-speed railway system.

museum
www.naturalsciences.be

Plattegrond - Plan d'étage - Etagenplan - Floor plan

museum

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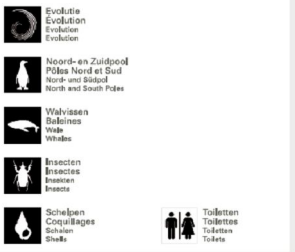

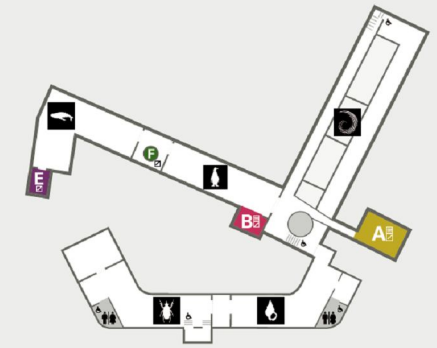

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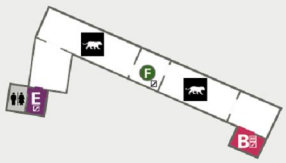

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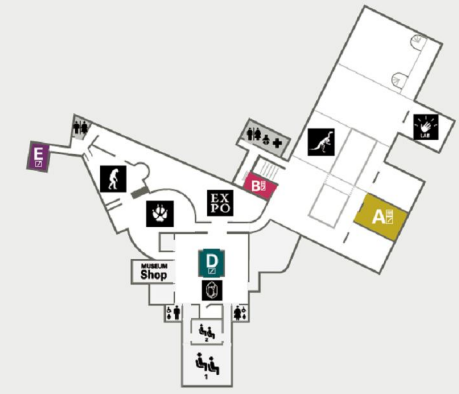

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5. Participants list

Alison Abrahams	European Public Health Alliance (EPHA)
Demosthenes Agrafiotis	National School of Public Health, Greece
Gabriella Almberg	EFPIA
Ariane Amberg	Swiss Mission to the EU
Franklin Apfel	World Health Communication Associates (WHCA)
Albena Arnaudova	World Health Organization, office to the EU
Paul Arteel	Gamian-Europe
Mazuy Aurelien	Servier
Sigita Bagdoniene	ECCA
Jorien Bakx	NIGZ
Luiza Bara	European Public Health Alliance (EPHA)
Christian Barnes	Edelman
Catherine Bates	Merck Serono
Luca Battistini	AESGP - Association of the European Self-Medication Industry
Nicolas Becuwe	TNS opinion
Nicola Bedlington	European Patients' Forum
Lena Bera	Eli Lilly and Company
Karin Bernadotte	
Nolwenn Bertrand	Edenred
Eva Maria Bitzer	University of education
Amanda Bogg	Health First Europe
Elena Bonfiglioli	Microsoft
David Boyd	GE Healthcare
Helmut Brand	Maastricht University
Alexander Britz	
Stephan van den Broucke	Université Catholique de Louvain
Kenneth Cafferkey	The HLS-EU Project
Dennis Carrington	Independant HL
Sara Eva Cebrian	MSD
Sabrina Cecconi	World Health Communication Associates (WHCA)
Leo Cendrowicz	Time Magazine
Rob Couter	
Stéphane Crets	CSR Europe ASBLI (NPO)
Anita Creusen	Maastricht University
Arthur Culbert	Saint Louis College of Pharmacy
Agata D'Addato	Eurochild
John Dalli	European Commission
Sarah Dauven	German Federal Ministry of Health
Bojan Davinic	EPSA (European Pharmaceutical Students' Association)
Emanuele Degortes	American Chamber of Commerce to the EU
Gerardine Doyle	The HLS-EU Project
Andrew Dyson	MSD
Rochelle Se Yun Eng	Microsoft
Marie-Louise Essink-Bot	Academic Medical Center (Dept. of Public Health)
Mikis Euripides	MSD (UK)
Maria Falcon	The HLS-EU Project
Laura Fernández Maldonado	Fundació Josep Laporte
Ezia Ferrucci	MSD Italy
Christofer Fjellner	MEP
Marleen Foets	Erasmus University Rotterdam
Stephan Fousek	Gesundheit Österreich GmbH
Mirjam Fransen	Academic Medical Centre, University of Amsterdam

James Fullam	University College Dublin
Aoife Gallagher	Fleishman-Hillard
Duarte Gaspar	European Commission
Antoni-Joan Gelonch-Viladegut	Sanofi
Giovanna Giacomuzzi	PGEU
Andromachi Giannopoulou	
Christiana-Dimitra Giannopoulou	
Jeanine van der Giessen	University Medical Center Utrecht
Stefan Gladilov	Faculty of Public Health, Medical University – Sofia
Jean Gordon	European Institute of Education and Social Policy
Marta Grosso	Centre for Health Education (CSESI), University of Perugia
Zamira Gurabardhi	Maastricht University, Faculty of Work and Social Psychology
Barbara Haake	
Henriette Hansen	South Denmark European Office
Catheirne Hartmann	European COPD Coalition
Stanimir Hasurdjiev	European Liver Patients Association
Iris van der Heide	National Institute for Public Health and the Environment
Annelies Hetharia	University Medical Center Utrecht
Maren Holoda	GIRP
Maria Iglesia Gomez	DG SANCO
Kaisa Immonen-Charalambous	European Patients' Forum
Pavlina Janova	
Brigitte Jencik	AEMH european Association of Senior Hospital Physicians
Janne Jensen	Department of social medicin, Karolinska Institut, Sweden
Susanne Jordan	Robert Koch Insitute
Aleksandra Jovic Vranes	University of Belgrade Medical School
Dolors Juvinya	University of Girona
Karin Kadenbach	S&D Austria
Alesia Kalbasko	Erasmus University Rotterdam
Martin Kastler	Member of the European Parliament
Lars Kayser	University of Copenhagen
Ilona Kickbusch	Graduate Institute of International and Development Studies, Geneva
Tanja Kimova	TNS Opinion
Kai Kolpatzik	AOK-Bundesverband
Barbara Kondilis	The HLS-EU Project
Molemisi Kono	Postgrad - Research Student
Nadine Konopik	Universität Frankfurt am Main
Gerrit Koopmans	Erasmus Universiteit Rotterdam – iBMG
Jaap Koot	Nederlands Institute of Public Health
Daniel Kropf	Universal Education Foundation
Maria del Carmen Lavid	MSD
Tamara Le Moine Dieulle	Health First Europe
Philippe Lehmann	HESAV Haute Ecole de Santé Vaud, Lausanne
Diane Levin-Zamir	National Director of Health Education and Promotion
John Lucy	Liverpool Primary Care Trust
Jennifer Lynch	The National Literacy Association
Helle Terkildsen Maindal	University of Aarhus, School of Public Health
Charlotte Malvy	Edenred
Fandel Marie-Hélène	Amgen sa
Marianne Massa	Health Promotion & Disease Prevention Directorate
Ursula Meidert	Institute of Social- and Preventive Medicine, Univeristy of Zurich
Ross Melzer	EurActiv.com
Monika Mensing	Landesinstitut für Gesundheit und Arbeit NRW (LIGA)
Osama Mohamed Elhassan	Sudanese Federal Ministry of Health

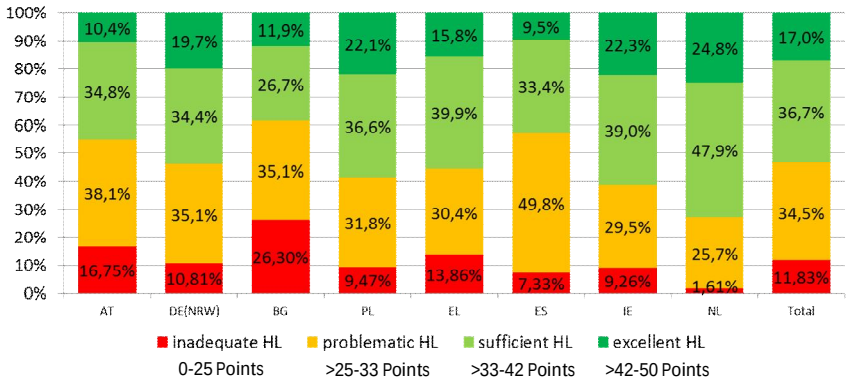
Guilherme Monteiro Ferreira	European Pharmaceutical Students' Association
Marco Musella	Mediserve srl
Anastassia Negrouk	European Organisation for Research and Treatment of Cancer
Christine Neumann	CSR Europe
Barbara Niedzwiedzka	Institute of Public Health Jagiellonian University Medical College
Ole Nørgaard Frandsen	University of Copenhagen
Don Nutbeam	South Hampton University
Sarah O'Brien	Health Service Executive
Ria Oomen-Ruijten	Member of the European Parliament
Ciara O'Rourke	MSD
Richard Osborne	Deakin University
Antonyia Parvanova	ALDE
Andrea Pavlickova	Epposi
Jürgen Pelikan	LBI Health Promotion Research
Sophue Peresson	International Diabetes Federation European region IDF Europe
Silvia Petak-Opel	MSD SHARP & DOHME GMBH
Lukas Pfister	Public Policy MER
Ray Manuel Pinto	Microsoft
Luis Pinto	Universal Education Foundation
Erica Poot	EFPIA
Sashka Popova	Faculty of Public Health, Medical University – Sofia
Andreas Preising	EFPIA
Marina Puddu	DG Sanco
Jany Rademakers	NIVEL
Beatrice Riley	Maastricht University
Karin Ringsberg	Nordic School of Public Health – NHV
Florian Roethlin	The HLS-EU Project
Gillian Rowlands	London South Bank University
Sonia Ruiz Moran	General Council of Pharmacists of Spain
Andrzej Rys	European Commission
Luis Saboga Nunes	School of Public Health, Lisbon
Laura Sahm	University College Cork
Lienke Sanderman	Maastricht University
Isabel De Santiago	Factulty of Medicine of Lisboa
Magda Savin	GIRP
Doris Schaeffer	Universität Bielefeld, Fakultät für Gesundheitswissenschaften
Hugo Schepens	DAIDALOS sc
Alexander Schroeder	Johnson & Johnson
Christoph Schwarz	Maastricht University
Gabriele Seidel	Medizinische Hochschule Hannover
Elena Shipkovenska	Faculty of Public Health, Medical University – Sofia
Elise Sijthoff	Fysio Educatief
Zofia Slonska	The HLS-EU Project
Torsten Soerensen	The Danish Continence Society
Kristine Sorensen	Maastricht University
Laurène Souchet	European Patients' Forum
Zoran Stancic	DG INFSO
Vivian Stoffels	Maastricht University
L. Suzanne Suggs	Università della Svizzera Italiana
Hildrun Sundseth	European Institute of Women's Health
Rosa Suñer	HPH Catalonia (Spain)
Kjell Sverre Pettersen	Akershus University College of Applied Sciences
Camilla Tavlo Christensen	University of Copenhagen
Kancho Tchamov	Faculty of Public Health, Medical University – Sofia

Pat the Cope Callagher	Member of the European Parliament
Josine van der Togt	University Medical Center Utrecht
Geesje Tomassen	Netherlands Institute for Health Promotion (NIGZ)
Sarka Travnicka	
Bart Vandewaetere	Nestlé
Laura Viluma	Erasmus University Rotterdam
Margaret Walker	EASL - European Association for the Study of the Liver
Tania Weng-Bornholt	MSD Merck Sharp & Dohme AG
Diane Whitehouse	The Castlegate Consultancy
Beate Wiegard	Institute for Quality and Efficiency in Health Care
Stefan Wild	MSD Merck Sharp & Dohme AG
Kajsa Wilhelmsson	Edelman
Michael Wilks	CPME
Jane Wills	London South Bank University
Daniela Wolf	Maastricht University
Stecy Yghemonos	EuroHealthNet
George Yiangou	Association of the European Self-Medication Industry (AESGP)

6. Key findings of the first European Health Literacy Survey

- While levels of health literacy differ considerably among the member states involved in the study, on average nearly every other citizen possesses a low level of health literacy. This result is a challenge not only for health professionals, but also for health systems at large.
- The health status of a country's population often positively correlates with the health literacy levels of that population. This means that a country with a low social health status will also possess a low level of health literacy. There is a remarkable social gradient not only for health status, but also for health literacy. This is true for all eight countries included in this study, irrespective of differences in the actual parameter value.
- People with very poor health status that use health services more than 6 times per year are also very likely to possess a low level of health literacy. This result presents specific challenges for healthcare services and professionals working in the health field.

Percentages of different levels of the general HL-Index in the 8 participating countries and the total sample of HLS-EU



- The general HL Index is based on means of all 47 items of the HLS-EU Instrument. It is standardized between 0 and 50, where 0 is the minimal possible health literacy and 50 is the maximal possible health literacy.

HLS-EU Consortium 2011: General Health Literacy in eight European Countries

Health literacy in the context of relevant EU Initiatives

Health is a major determinant of the EU2020 strategy[1] and its emphasis on promoting smart, sustainable and inclusive growth in particular. Furthermore, the European Health Strategy identified "promotion of health literacy programmes for different age groups" as one of the action points.[2] In our view, health literacy in particular can contribute to these 2020 priorities in the following way:

- **Smart growth**: innovation also has a vital role to play in healthcare. However, such innovation can only lead to better health if health consumers are able to make use of these innovations. As such, by informing health consumers about the proper use of innovation, higher health literacy results in better health. As health is a precondition for productivity and growth, better health can also result in better innovation;
- **Sustainable growth**: our health systems require more and more resources. As health literacy helps users to navigate the health system, it contributes to a more efficient use of healthcare resources;
- **Inclusive growth**: Member States do not only differ in economic power but also in the health status of citizens. In order to improve growth across the continent, there must also be standard improvements in health. Furthermore, increasing health literacy helps to overcome unequal access to healthcare and therefore fosters social and territorial cohesion.

However, the results of the recent European Health Literacy Survey have shown that there is a long road ahead before an adequate level of health literacy across Europe is achieved.

This is why we find it disappointing that although health literacy has been recognized as an action point in the health strategy, it is no longer mentioned in the new health programme. Given the important role of patients and citizens as co-producers of health, it is vital to sustainable health systems that they are empowered to take informed health-related decisions. Improved health literacy throughout the EU can greatly help policymakers achieve this objective.

Policy Recommendations

In view of

- the contribution of health literacy to growth and productivity;
- the importance of health literacy in overcoming health inequalities, within but also across Member States;
- the role of citizens and patients in health,

we propose the following policy recommendations

- Define concrete objectives and ways to empower citizens and increase health literacy. Health literacy should therefore become a priority in the European Commission's new programme, and concrete cross-sector, multi-stakeholder collaboration should be promoted;

[1] COM(2010) 2020, COMMUNICATION FROM THE COMMISSION. EUROPE 2020 A strategy for smart, sustainable and inclusive growth

- Provide funds to support initiatives that improve health literacy, in particular amongst the most vulnerable population;
- Go beyond the current Directive on Information to Patients and develop a more comprehensive health information strategy;
- Ensure that health literacy, as a social determinant of health, is included in relevant international discussions on health promotion systems, reducing health disparities, and promoting sustainable development and awareness of non-communicable diseases;Include health literacy in the education and evaluation of health practitioners;
- Integrate health literacy into school curricula;
- Promote the use of best practice when developing new health literacy measures and the development of a web of evidence on their validity across settings;To promote health literacy interventions and ways they can be developed and applied;
- To promote further research on how health literacy can be used to optimize disease prevention and health promotion;
- To strengthen the knowledge and evidence base for measuring and assessing health literacy.

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The European Health Literacy Project 2009-2012

The European Health Literacy Survey

Executive summary

November 2011

Executive Agency for Health and Consumers

Index

1. Foreword

The European Health Literacy Conference in November 2011 in Brussels is the culminations of three years of work in the consortium of nine European institutes who have taken part in the European Health Literacy Project (HLS-EU) from 2009-2012. The main objectives of the project was to measure health literacy in eight European countries; to establish a network of professionals who can take up the challenges of regarding the advancement of health literacy in Europe; and to organize national initiatives such as advisory boards or groups who can promote health literacy at national levels.

At the point of the European Health Literacy Conference the mission is completed. Health literacy is being adapted to the European health agenda and we are delighted to announce that the European Health Literacy Conference is co-hosted with three members of the European Parliament Mr. Christofer Fjellner, Sweden; Mr. Pat the Cope Gallagher, Ireland and Mrs. Karin Kadenbach, Austria and that the opening speech is made by European Commissioner for Health and Consumers mr. John Dalli.

175 stakeholders from a broad variety of European and national institutions, organizations and businesses are present in Brussels to discuss the results of the European Health Literacy Survey and find solutions to the health literacy gap identified. In average *nearly every second person participating in the survey has limited health literacy* as measured by the means of the newly developed HLS-EU questionnaire. There are considerable differences seen between the eight countries in the survey, and by critical reflecting on the results we can learn from each other and pave the way for better health within our national remedy. The HLS-EU consortium has provided the facts and figures on health literacy, now it is time to dare to compare and move to action!

The health literacy gap in Europe needs to be addressed. The necessary steps are two-sided: the knowledge, motivation and competences of citizens to take qualified health decisions need to increase, and society as a whole needs to decrease its complexity to better guide; facilitate and empower citizens to manage health in a sustainable manner. All efforts are needed to strengthen the role of citizens in managing health by re-designing systems, roles and curricula of professionals to meet the challenge of the health literacy gap.

By recognizing health literacy as a social determinant for health and a driver for change in terms of health and quality of life actions can be taken to impact the current situation.

Helmut Brand
Project leader, the European Health Literacy Project (HLS-EU)
Professor of European Public Health
Maastricht University

November 2011

2. The European Health Literacy Project

The aim of the European Health Literacy Project (HLS-EU) is to establish the issue of health literacy in Europe.

The objectives are to:

- adapt a model instrument for measuring health literacy in Europe
- generate first-time data on health literacy in European countries, providing indicators for national and EU monitoring
- make comparative assessment of health literacy in European countries
- create National Advisory Bodies in countries participating in the survey and to document different valorization strategies following national structures and priorities.
- establish a European Health Literacy Network

The HLS-EU Project is co-financed by the European Commission's Executive Agency for Health and Consumers (EAHC) to take place from 2009-2012 and is managed by the HLS-EU consortium with Maastricht University as leading partner and eight institutes are associated partners:

- Maastricht University, the Netherlands
- National School of Public Health, Greece
- University College of Dublin, National University of Ireland,
- Ludwig Boltzmann Gesellschaft GmbH, Austria
- Instytut Kardiologii, Poland
- University of Murcia, Spain
- Medical University - Sofia, Bulgaria
- National Institute of Public Health and the Environment, The Netherlands
- Landesinstitut für Gesundheit und Arbeit des Landes Nordrhein-Westfalen

More than twenty institutes from Europe and abroad follow the project as collaborating partners and an updated list can be found at www.health-literacy.eu.

3. The European Health Literacy Survey

The European Health Literacy Survey aims to produce first time population data on health literacy. The survey results will be used to inform European, regional and national health policies, to support political and professional decision-making and to bring the health literacy agenda into public discourse. The health literacy measure is foreseen to be part of the European Union's health reporting and monitoring systems. By creating the network for professionals called Health Literacy Europe a platform for knowledge exchange and a means to generate expertise on health literacy in Europe can support an on-going refinement of the tool and expansion of countries included in the data pool.

The HLS-EU consortium has designed the HLS-EU-Q, the tool to measure health literacy. It is grounded in a working definition and a conceptual model developed by the consortium on the basis of a scientific systematic literature review.

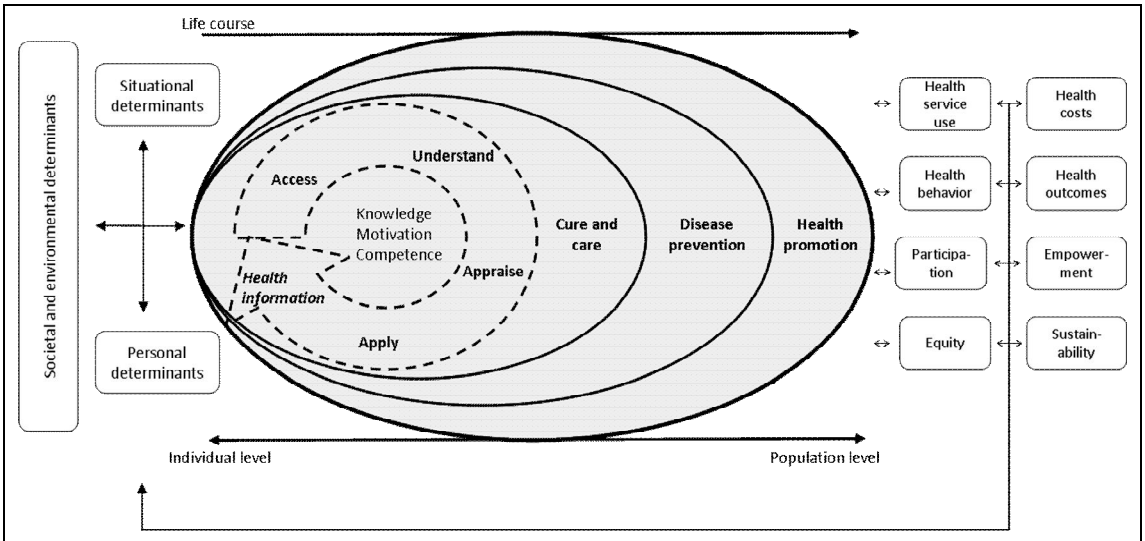
HLS-EU definition of health literacy

The definition of HLS-EU is an integrated definition developed from a review of more than 15 definitions of health literacy found in scientific literature:

> *Health literacy is based on general literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information to make judgments and take decisions in terms of healthcare, disease prevention and health promotion to maintain and improve quality of life throughout the life course.*

The HLS-EU conceptual model and matrix

The conceptual model integrates an individual and systemic approach by focusing on the three domains of health, namely being ill/healthcare; being at risk/disease prevention and being healthy/health promotion. It identifies four important modes of information processing: Finding information; understanding information; evaluating information and applying information to one's own life in order to take a qualified health decision. These domains and modes combined yields a matrix with 12 sub-dimensions. This matrix has been the foundation for the HLS-EU-Q tool, where every sub dimension is operationalized to include 3-5 specifically formulated items, resulting in 47 items in total measuring the HLS-EU concept of health literacy. The items are either related to a situation or to a task where processing health relevant information is required in terms of healthcare, disease prevention or health promotion. The respondents have rated the perceived difficulty of every task or situation with answers on a Likert scale with four categories (very easy, easy, difficult, very difficult).



The European Health Literacy consortium 2011: HLS-EU conceptual model

	Access	Understand	Appraise	Apply
Healthcare				
Disease prevention				
Health promotion				

The European Health Literacy consortium 2011: HLS-EU –Q matrix

HLS-EU data collection

The European Health Literacy Survey was conducted by TNS Opinion on behalf of the HLS-EU consortium applying Eurobarometer standards in methodology and sampling procedures. The Computer Aided Personal Interview technique (CAPI) was used for data collection. The sample includes 1000 respondents aged 15 years in each of the eight partner countries resulting in a total database of approximately 8000 people.

HLS-EU data analysis – The four HLS-EU indexes

The data analysis was carried out by the Austrian team lead by Professor Jürgen Pelikan. Four health literacy indexes have been developed to provide overviews of health literacy levels. One index is measuring *general health literacy (General-HL)* and three sub-indexes concern the three domains of health: 1) health literacy for being ill/healthcare *(HC-HL)*, 2) health literacy for being at risk/disease prevention *(DC-HL)* and 3) health literacy for being healthy/health promotion *(HP-HL)*.

To simplify comparison of the mean of the 47 health literacy items, the indexes were standardized on a unified metric with a minimum of 0 and a maximum of 50, where 0 represents the least possible health literacy and 50 represents the best possible health literacy. Respondents with higher index scores are considered more health literate than respondents with lower scores, since they perceive situations or tasks where health information processing apply easier or less difficult than respondents with lower scores. When interpreting differences of index scores between sub-populations, it is of importance to be aware, that the concept and measurement of health literacy generally and also in the HLS-EU study is relational and generated by the interaction of individual competences and contextual and situational demands. Therefore differences in scores can be attributed to different personal competences in the populations and to different contextual and situational demands for these populations.

The indexes are highly correlated (0,7-0,8 for sub-dimensions within HL-General and 0,5-0,65 between sub-dimensions). Thus the indexes are similar enough to measure a common concept of health literacy, and yet diverse enough to indentify specific differences between the areas of healthcare, disease prevention and health promotion.

The means for the four indexes are somewhat different and standard deviations also vary. Furthermore in terms of the inter-correlations of indexes the means and standard deviations vary considerably between the eight participating countries in the survey.

	General-HL	HC-HL	DP-HL	HP-HL
Mean	34,00 30,90 (BG) 37,34 (NL)	34,70 32,93 (AU) 38,25 (NL)	34,39 30,99 (BG) 37,96 (NL)	32,57 28,21 (BG) 35,89 (NL)
Standard Deviations (S.D)	7,98 9,07 (BG) 6,28 (BG)	8,30 8,26 (AU) 6,70 (BG)	8,77 9,99 (BG) 7,00 (NL)	9,13 10,04 (BG) 7,54 (NL)

For General-HL the largest difference is seen between Bulgaria and the Netherlands. For HC-HL the biggest difference is seen between Austria and the Netherlands. For DP-HL the largest difference is seen between Bulgaria and the Netherlands and this is also the case for HP-HL.

HLS-EU levels of health literacy

When measuring health literacy (and literacy) it is common to define ranges dividing respondents into groups having different levels of health literacy from low or limited health literacy to adequate and excellent health literacy relevant for decision-making, action or

participation in tasks and roles concerning health. Especially the ranking aims to identify groups with problematic levels of health literacy for individuals and the society. The HLS-EU study distinguishes between four ranges of health literacy:

- *Inadequate level of health literacy:* *0-25*
- *Problematic level of health literacy:* *>25-33*
- *Sufficient level of health literacy:* *>33-42*
- *Excellent level of health literacy:* *>42-50*
- *Limited level = Inadequate+problematic health literacy:* *0-33*

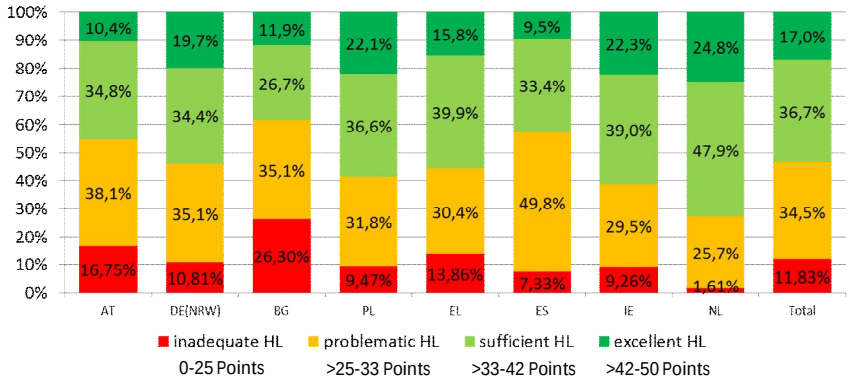
The threshold for inadequate health literacy implies a score of 25, which equals 1/2 of the maximum 50 score possible. Likewise the problematic health literacy implies a score of 33, which is 2/3 of the maximum score possible. The level for excellent health literacy equals a score of 42 or more, which is 5/6 of the maximum score possible. By summarizing respondents with inadequate and problematic health literacy a group is created, which can be identified as having *limited health literacy.*

4. How big is the problem of limited health literacy in Europe?

In the HLS-EU survey 11,83% of respondents in the total sample have inadequate health literacy, and 34,47% have problematic health literacy, which means that 46,3% have limited health literacy. In other words, nearly every second person participating European has limited health literacy when using the HLS-EU-Q and HLS-EU index for general health literacy.

The differences between participating European countries in proportions of limited health literacy are considerable:

Percentages of different levels of the general HL-Index in the 8 participating countries and the total sample of HLS-EU



- The general HL Index is based on means of all 47 items of the HLS-EU Instrument. It is standardized between 0 and 50, where 0 is the minimal possible health literacy and 50 is the maximal possible health literacy.

HLS-EU consortium 2011: General Health Literacy in eight European Countries

From the survey it can be observed that the difference between the country best off and worse off is similar when observed for all four indexes: General health literacy, healthcare health literacy, disease prevention health literacy and health promotion health literacy.

	Inadequate health literacy		Problematic health literacy		Limited health literacy	
General HL	1,6% (NL)	26,3% (BG)	25,7% (NL)	35,1% (BG)	27,3% (NL)	61,4% (BG)
Healthcare HL	2,3% (NL)	9,5% (ES)	21,7% (NL)	41,4% (ES)	23,9% (NL)	50,9% (ES)
Disease Prevention HL	3,0% (NL)	23,9% (BG)	21,5% (NL)	27,9% (BG)	24,5% (NL)	56,8% (BG)
Health promotion HL	8,8% (NL)	41,8% (BG)	27,8% (NL)	27,9% (BG)	36,6% (NL)	69,7% (BG)

Limited health literacy = inadequate health literacy + problematic health literacy

5. Is there inequality in health literacy or a health literacy gap in Europe?

Evidence and debate in public health suggest that there is not only social inequality or a social a gradient or a gap for *health,* but also a social gradient or gap for *literacy* and *health literacy*. Indeed, the HLS-EU survey observes that there are significant bivariate correlations between health, measured as self-assessed health ("How is your health in general") and socio-demographic or socio-economic characteristics of respondents for age, employment status, self-assigned social status, financial deprivation and education. Thus a social health gap is also being demonstrated by the HLS-EU survey.

Correlation	Health and socio-economic or socio-demographic factors	Functional health literacy and socio-economic or socio-demographic factors	Index of general health literacy (HG-HL)
Age	0.44	-0.30	-0.15
Employment status	0.31	-0.26	-0.15
Self-assigned social status	0.27	0.30	0.30
Financial deprivation	0.22	-0.21	-0.34
Education	-0.22	0.35	0.25

The social health gap holds true for functional health literacy too, as measured by the Newest Vital Sign test. This is a test using a food label of an imaginary ice cream container, which is presented to respondents, who are asked to answer six literacy and numeracy questions related to the label. It has a range from 0-6 points, where 2 points or less indicate a high likelihood of limited functional health literacy, 3-4 points indicate the possibility of limited functional health literacy and 5-6 points are indicating adequate functional health literacy. The index of general health literacy correlates nearly in the same order as functional health literacy. There are also considerable correlations on a bi-variate level between

literacy (- 0.24) and general health literacy (-0.30) with self-assessed health. The interrelation between general health literacy and self-rated health yielded a somewhat dampened, but still significant and considerable correlation (-0.12), when controlled for age, education, social status, employment status, financial deprivation, exercise, body-mass-index and functional health literacy.
Thus, it can be concluded that there is a remarkable social gradient for health literacy in Europe which has to be tackled by policy and practice in its own right. Considerable differences have been found between participating European countries for social gradients affecting general and specific health literacy. More detailed analysis is needed to explore these differences, so that countries can learn from each other how to reach higher levels of health literacy.

6. What are specific vulnerable groups with highest risk of limited health literacy in Europe?

Proportion of sample with limited health literacy	Percentage	Vulnerable group
More than 75%	79,2%	Lowest level of education (0)
	77,5%	Self-rated health as "very bad"
More than 67%	72,8%	Social status as "very low"
	70,8%	Self-rated health as "bad"
	67,8%	Lowest score on functional health literacy test (NVS=0))
Above 50%	65,1%	Low level of education (1)
	63%	High financial deprivation
	60,4%	Age 76 years or more
	59,2%	Low score on functional health literacy test (NVS=1)
	58,6%	Widowed
	58,5%	Social status as "low"
	58,4%	Self-rated health as "fair"
	57,8%	6 or more doctor visits in the last 12 months
	57,2%	66-75 years old
	56,8%	Retired
	56,4%	Relative low education
	53,9%	Unemployed
	53,7%	Relative score on functional health literacy test (NVS=3))
	52,6%	3 or more hospital service uses in the last 12 months
	51,9%	Social status "lower middle"

The HLS-EU survey observes a number of groups of respondents who exceeds 50%, 67% and 75% of limited health literacy in the total sample. Thus vulnerable groups include the socio-economic deprived, but also people with worse health or higher frequencies of health service use have higher risks to also have limited general health literacy. This in turn produces a specific challenge for healthcare services, since the characteristics of these vulnerable groups with limited general health literacy are a high number of visits to general practioner and hospital, and therefore it will be necessary to develop specific strategies to

improve or compensate limited health literacy of these vulnerable groups in Europe. When combining some of the below mentioned categories, even higher levels of vulnerability for certain sub-populations result, and there are also higher levels of vulnerability in sub-groups in those countries which have lower levels of health literacy.

7. How do countries differ in socio-demographic, socio-economic, health status and health service use?

Socio-demographic and socio-economic factors

The distribution of important socio-demographic, socio-economic and health related covariates of health literacy in different countries included in the HLS-EU study, can give important clues for the interpretation of country differences.

Age

While the grand mean of the age distribution in all countries is about 46 with moderate variation, Germany´s sample population is on average significantly older (more than 50 years). And the Irish population is with an average of about 45 years the youngest of the country populations in the total sample.

Education

By means of education (ISCED Levels from 0 to 6) it is observed that the Netherlands (ISCED 3,55) and Ireland (ISCED 3,62) have considerably higher average ISCED classified education than the average and Spain with a considerably lower (ISCED 2,72) one.

Financial deprivation

The financial deprivation score (z-Values) shows considerable variations between countries. While respondents in Austria (-0,31 S.D.), Germany (NRW) (-0,41 S.D.), Spain (-0,44 S.D.) and the Netherlands (-0,63 S.D.) perceive less financial deprivation than average (average is 0), sample populations in Bulgaria (0,85 S.D.), Greece (0,66 S.D.) and Ireland (0,22 S.D.) perceive more.

Self-perceived social status

Self-perceived social status (on a scale from 1 to 10) shows remarkable variation mainly between two countries. While the total mean is 5,54; respondents in the Netherlands perceived their status rather high with an average of 6,90, while the Bulgarian respondents rated themselves lower on an 4,27 level.

Employment and retirement

The status of employment is an important covariate, because it differentiates between the unemployed and the retired which are two vulnerable groups with high likelihood of low health literacy. While the average percentage of unemployed for all 8 countries is 8,1%, its mainly the Netherlands (2,0%) and Austria (2,3%) with considerably lower portions of sampled unemployed. Spain (13,9%) and Bulgaria (12,2%) on the other hand have considerably higher shares.

Retired are 22,6% of respondents in the total sample . Particularly high rates of retired populations were sampled in Germany (NRW) (30,2%), Austria (27,8%) and Poland (26,0%). While Ireland (11,5%) and the Netherlands (16,7%) have remarkably small rates of retired populations in the sample.

Health related factors

Self perceived health was measured on a scale with the categories 1=very good, 2=good, 3=fair, 4=bad and 5=very bad, and shows a differentiated picture in the 8 countries. The total mean is 2,18. The Irish (1,82), the Greek (1,90) and the Austrian (2,02) populations rated their health substantially better, while mainly the Bulgarian sample population (2,54) rated it´s health poorer than other populations.

In the total sample 35% of respondents indicated one or more long-term illnesses or health problems (lasting at least 6 month or longer). While in Greece only 27,7% indicated long term health problems, and in Ireland only 28,8%, the Netherlands are outliers in the other direction. 42,1% of the Netherland sample population indicate long-term health problems.

Health Service Use

Use of emergency care

In the total survey sample 73,3% of the population stated no emergency service contact in the last 2 years. 20,4% indicated 1-2 contacts, 4,3% 3-5 contacts and 1,9% 6 or more contacts. While the distributions in most countries are similar there are differences in the shares of the no emergency contact populations. While only 58,8% of the Netherland and 63,3% of the Spanish population have not used an emergency service, 84,1% respective 82,4% in Greece and Germany indicated no use of emergency services. In the other categories the Netherlands have 27,5% (1-2 contacts), 7,4% (3-5 contacts) and 1,9% (6 or more contacts) which are constantly higher shares than in the other countries.

Doctor visits

19,0% of respondents in the total survey sample indicated that they had not been to a doctor in the last 12 month. 40,6% specified 1-2 visits, 22,0% 3-5 visits and 18,4% 6 or more visits. Again the distributions are similar in the different countries. Greece has the largest share (29,3%) of respondents who had not been to a doctor while Spain (28,8% indicated between 3 and 5 doctor visits) and Austria (27,6% indicated between 3 and 5 doctor visits) have considerable higher portions in the sample populations regarding this category.

Use of hospital service

In the total survey sample 73,0% of the respondents declare not to have used a hospital service in the last 12 month. 21,3% indicate 1-2 hospital stays, 3,7% indicate 3-5 hospital stays and 1,9% quote 6 or more hospital stays in the past 12 month. Ireland with 57,1% and the Netherlands with 60.9% are the 2 countries with substantial lower shares of non-hospital users in the sample, and accordingly (Ireland 32,2%; Netherlands 27,5%) together with Austria (26,6%) those countries with the higher than average shares in the 1-2 hospital stays category. Poland and Bulgaria on the other hand have with 85,4% respectively 83,8% large portions of non-hospital users in the sample and consequently with 12,3% (for Poland) and 13,2% (for Bulgaria) the smallest shares in the 1-2 hospital stays category.

Use of other health services

34,5% of respondents in the total sample specified that they have not used services from other health professionals in the last 12 month. 45,4% used services 1-2 times, 12,8% 3-5 times and 7,3% 6 times or more. While the Netherlands with 12,3% and Austria with 16,7% have particular small sampled shares of people who quoted no service use, 51,7% of the Bulgarian sample indicated no service use. While the Austrian sample shows noteworthy high shares of respondents for the categories 1-2 times use (55,1%) and 3-5 times use (20,9%), the Netherlands are with a share of 23,7% an extreme outlier in the otherwise quite homogenous “6 times or more” category.

Does health literacy influence health care use and cost of health care?

There is some international research and discussion on consequences of health literacy for healthcare use and healthcare costs. While the question concerning influences of health literacy on health care costs cannot be answered at all, due to the design of the HLS-EU study, there are some tentative results for the influence on healthcare use. There are significant but rather low correlations between General-HL and the frequency of healthcare use, which is somewhat different for each type of healthcare use: for emergency services (-.06), for doctors (-.12), for hospitals (-.06), for other health professionals (.06). But in multi-variate analyses these correlations vanish. Thus at the present stage of analyses, no direct effects of health literacy on frequency of healthcare use can be demonstrated by this study.

How can the health literacy differences between the member states be explained?

Remarkable differences in level and variation of health literacy, in social gradients affecting health literacy and in size of vulnerable groups with limited health literacy have been found between the eight countries participating in the HLS-EU study. These differences can only be partly explained by differences in socio-demographic or socio-economic composition of the national samples. There is room also for effects of different personal competences of respondents and of differences in demand for high health literacy in different social and cultural contexts, hence more detailed and complex analysis is needed to disentangle the different kinds of possible effects.

What follows from these results for policy and practice?

Limited health literacy by its size and distribution is a relevant problem for health policy and practice in Europe, but to a different degree in different countries. There is a notable social gradient not just for health or literacy, but also for health literacy. For certain vulnerable groups, limited health literacy affects the majority of respondents. These results indicate specific challenges for health care services and professionals working in that field. Therefore, European and national policy and practice will have to develop specific public health and health promotion strategies for tackling the problems affiliated with limited health literacy for people and institutions. There is a certain amount of international experiences which can be used, adapted and further developed for the situation in Europe and specific member states. The strategies will have to be a good mix of better educating and informing people, of improving the readability and navigability of existing health (care) systems and of enhancing communication competencies of health (care) professionals. For vulnerable groups, specific compensatory interventions will have to be applied.

Where is further analysis and research needed?

The data gathered by the HLS-EU study are so rich, manifold, diverse and complex that further more detailed multi-variate analyses of these data are needed. That holds true primarily for differences of the four kinds of health literacy indexes, differences between participating countries and the complex relationships of health status, health literacy and health services use. By following the Eurobarometer methodology, only EU-citizens have been included in the samples of HLS-EU. Therefore, the HL of considerable minorities of migrants living in Europe has not been included in this survey, and should be explored by further specific studies.

8. Policy recommendations for advancing health literacy in Europe

The recommendations of the European Health Literacy Project 2009-2012 aim to initiate and support research, policy and action on health literacy as a means to assist in reducing disparities in the promotion of health, wellbeing, and sustainable development, and to the pursuit of equity within and between countries, in the national, European and global context.

The key priorities should specifically concern

- The increase of health literacy in the population making it easier for citizens to manage their own health
- The decrease of complexity within systems making it easier for citizens to navigate health (care) systems and manage their own health.

The policy recommendations include to

- Define concrete objectives and ways to empower citizens and increase health literacy. Health literacy should therefore become a priority in the European Commission's new programme, and concrete cross-sector, multi-stakeholder collaboration should be promoted;
- Provide funds to support initiatives that improve health literacy, in particular amongst the most vulnerable population;
- Go beyond the current Directive on Information to Patients and develop a more comprehensive health information strategy;
- Ensure that health literacy, as a social determinant of health, is included in relevant international discussions on health promotion systems, reducing health disparities, and promoting sustainable development and awareness of non-communicable diseases;Include health literacy in the education and evaluation of health practitioners;
- Integrate health literacy into school curricula;
- Promote the use of best practice when developing new health literacy measures and the development of a web of evidence on their validity across settings;To promote health literacy interventions and ways they can be developed and applied;
- To promote further research on how health literacy can be used to optimize disease prevention and health promotion;
- To strengthen the knowledge and evidence base for measuring and assessing health literacy.

9. Health Literacy Europe

Health Literacy Europe is the network for professionals in Europe launched by the HLS-EU consortium autumn 2010 at the European Health Forum Gastein in Austria. In a year's time the professional network has grown to more than 125 members. The network is hosted by the department of International Health, Maastricht University and the intention is to develop regular routines in terms of news letters, events and other platforms for knowledge exchange. The network can serve as vehicle for development of health literacy expertise nationally and internationally and play an essential role for capacity building of professionals to the advancement of health literacy in Europe.

10. Concluding remarks

The European Health Literacy Project has provided a solid knowledge base for further development of health literacy. The sincere hope is that more countries will participate in the European Health Literacy Survey and thus add to the data pool. This gives opportunities for national and European cross-national comparisons, and the idea is to include health literacy into European monitoring systems to follow the developments in the future.