STOA Workshop
Health Literacy in Europe

Participants' booklet

WORKSHOP
STOA | SCIENCE AND TECHNOLOGY OPTIONS ASSESSMENT
WEDNESDAY 01.07.2015 – 14:30–17:00
PAUL-HENRI SPAAK BUILDING – ROOM J050
REGISTRATION BY 26.06.2015 on https://www.stoa.europa.eu/stoa

Health Literacy in Europe
Empowering patients – how can technology contribute to improving health literacy?

CHAIR
Paul Bulcke, MEP and STOA Chair

MODERATOR
Helmut Brand, University of Wuppertal

SPEAKERS
Roberto Bertolini, WHO, Representation to the European Union
Kristine Sarum, University of Maastricht
Kata Puhlman-Charkutich, European Society for Nutrition (ESPEN)
Marc Gagg, European Health Information Association (EHI)
Ivo Molema, Pharmaceutical Group of the European Association (PGEA)
Vesna Blazic, European Centre for Disease Prevention and Control (ECDC)
Tejo Peena, DG Connect, European Commission

CLOSING REMARKS
Kati Kadenbach, MEP

EPRS | European Parliamentary Research Service

Scientific Foresight Unit (STOA)
PE 563.477
STOA Workshop

HEALTH LITERACY IN EUROPE
Empowering patients - how can technology contribute to improving health literacy?

Participants' booklet

1 July 2015, 14:30 - 17:00
European Parliament, Brussels
Paul-Henri Spaak building, room 7C050
Follow us on Twitter @EP_ThinkTank and use #eHealthSTOA to talk about the event

Prepared by Gianluca Quaglio and Sara Cagol of the STOA Secretariat.

Available at:
http://www.europarl.europa.eu/stoa/cms/home/events/workshops/literacy
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# 1. PROGRAMME

Chair: Paul Rübig, MEP and STOA Chair  
Moderator: Helmut Brand, University of Maastricht

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<td>The role of EU policy in ensuring that innovative solutions are developed to improve health literacy</td>
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2. HEALTH LITERACY: AN INTRODUCTION

Definition of health literacy
Health literacy refers to the capacity to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the healthcare system, in the marketplace, and in the political arena. It concerns the knowledge and competences of people to meet the complex demands of health, particularly in modern society.

A widely-accepted definition is the following: health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements, and take decisions, in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.

Health literacy is necessary to understand instructions for self-care, to plan and achieve desired lifestyle adjustments, to know how and when to access health care, etc. With the demographic change, the rise in chronic diseases and a scarcity of health personnel, health literacy will play a central role: it recognizes the critical role of citizens and patients in health care and health systems.

Therefore, including health literacy in EU policy (health and other relevant areas) as an overarching objective contributes to the overall objectives of EU’s health strategy, which is to strengthen citizen’s role with regard to their health, to improve health outcomes and to reduce the growing burden on healthcare systems.

The importance of innovation for health literacy in Europe
The world of health applications is set to transform healthcare in the coming years. With global mobile broadband subscriptions predicted to reach 9.3 billion in 2019 alone, the mobile platform will make up an increasing portion of e-health. This is already evident in the growing use of health applications. About 97,000 m-health applications are available on different platforms: 70% of these are aimed at citizens. The other 30% are designed for healthcare professionals by facilitating the access to patient information, consultations, monitoring, diagnostic imaging and information on medicines.

Mobile applications have the advantage of existing on a device that is already in everyone’s hands at almost any time of the day. In addition, mobile applications help patients and citizens to access health information about health prevention and healthy lifestyles, and to manage their disease. In turn, increased availability of health information across borders presumes skilled citizens and patients. But are they health literate enough to make best use of this technology? In fact, health literacy levels across the EU are still rather low, with persistent inequalities across and within Member States.
Low health literacy has proven to have a direct impact on the management of chronic conditions, productivity levels, mortality rate and overall healthcare costs. With the emergence of new technologies, citizens are faced with more complex decisions to make. For example, with progress in genomics people will be required to better understand the health issues that could affect them.

In an era where technology and innovation are key to improve the efficiency of healthcare systems and to ensure better health outcomes for European citizens, it is critical to guarantee that patients and citizens have the capacity to make sound health decisions about their health.

Moreover, in light of current austerity measures in Europe, the demographic change and the increasing prevalence of chronic diseases, it is also critical to make the most efficient use of existing resources, and ensure that our health systems are sustainable to bear the burdens of the coming decades.

Furthermore, the extent of information available and the fact that health applications are not controlled, there is a risk of misinformation or wrong self-diagnosis. According to the recent Eurobarometer “European citizens’ digital health literacy”, 59% of Europeans used the internet to search for health related information within the last 12 months. However, 41% did not think the information came from a trustworthy source, with noticeable discrepancies across the various Member States. Improving health literacy may help citizens and patients to navigate in the promising new world of e- and m-health.

The impact that the availability and visibility of data, graphs and pictures capturing people’s health has on patients, should not be underestimated. It has the power to close the gap between public health campaigns and implementation.

The significant cross-border element of e-health and its related challenges, not least data protection and safety, should also be taken into account when discussing policies surrounding new technologies.

Objectives of the STOA workshop
It is of utmost importance that the role of European citizens and their health literacy be considered when thinking about innovative policies, and more concretely, e-health and m-health initiatives. The widespread adoption and use of mobile e-health technologies, which is opening new and innovative ways to improve health and health care delivery, will be a key tool to enhance health literacy.

The objective of the STOA workshop will therefore be to discuss with experts the opportunities and challenges new technologies for health literacy. It will also assess how increasing health literacy levels in Europe should be a key consideration when developing upcoming e-health and m-health based innovative healthcare solutions. The workshop will also aim to explore how such innovative technologies could ultimately improve overall health outcomes.
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3. CHAIR

Paul Rübig MEP and STOA Chair

Paul Rübig was elected as the STOA Chair for the first half of the European Parliament's 8th legislature having previously served as Chair from 2009 to 2012 and as First Vice-Chair from 2012 to 2014.

Born in Upper Austria, Paul Rübig has been a member of the European Parliament since 1996 and belongs to the European People's Party (EPP).

He is the owner of an Austrian blacksmith company and has a degree in Business Administration, Marketing and Production Engineering from the University of Linz, Upper Austria. He is married and has two children.

Paul Rübig is a full member of the Committee on Industry, Research and Energy and of the Committee on Budgets. He is Vice-Chair of the Delegation for relations with the Korean Peninsula and substitute member of the Delegation for relations with Switzerland, Norway and of the EU-Iceland Joint Parliamentary Committee.

He is also a substitute member of the European Economic Area (EEA) Joint Parliamentary Committee. Furthermore, Paul Rübig is a substitute member in the Committee on Development. Paul Rübig is very active in the field of the small-scale business promotion.

He is president of SME Global, a working group of the International Democrat Union (IDU), whose objective it is to support small and medium-sized enterprises (SME) and to improve their business environment.
4. MODERATOR

Helmut Brand, University of Maastricht

Helmut Brand is Jean Monnet Professor of European Public Health and head of the Department of International Health at Maastricht University, The Netherlands.

He studied Medicine in Düsseldorf and Zürich and earned a Master in Community Medicine from London School of Hygiene and Tropical Medicine and London School of Economics. Professor Brand is a specialist in Public Health Medicine.

After working in several Health Authorities and Ministries of Health in Germany he was director of the Public Health Institute of North Rhine Westphalia. Since then European Integration in Health is the main topic of his work.

He is past-president of the Association of Schools of Public Health in the European region (ASPHER), president of the European Health Forum Gastein (EHFG) and co-chair of the European Alliance for Personalised Medicine (EAPM).

As policy advisor he serves e.g. on the European Advisory Committee on Health Research (EACHR) of WHO Europe and on the Expert Panel on ‘Investing in Health’ for the European Commission.

Maastricht University, the most international university in the Netherlands, stands out for its innovative approach to learning and international outlook. With almost 16,000 students and 4,000 staff, Maastricht University offers a wide choice of academic programmes, all of which are designed to bring out the best in its students.

Researchers at Maastricht University work in multidisciplinary teams and in close cooperation with international institutes, business and industry. The high-quality researchers have attracted international attention by taking the lead in several large European research projects. Maastricht University’s research portfolio continues to attract national and international top researchers.
5. SPEAKERS

Kristine Sørensen, University of Maastricht

Kristine Sørensen is working at Maastricht University in the field of health literacy and European Public Health.

She has played a key role in developing the European health literacy field by launching national and regional networks as well as organizing European health literacy conferences to strengthen knowledge exchange and networking among stakeholders from policy, research and practice.

Kristine Sørensen has been project coordinator for the Health Literacy Survey (HLS-EU) in Europe hosted by the department of International Health at Maastricht University.

She has since 2007 been involved in the bachelor and master of European Public Health in various functions. Furthermore she is a visiting lecturer at Centre for European Studies in Maastricht and at Copenhagen University in Denmark.

Being Danish of origin her educational background is in medicine and public health with a bachelor/master degree in Public Health Science from Copenhagen University.

Key message

Recent research has shown health literacy to be a public health challenge for populations in many European countries. Health literacy refers to the ability to find, understand, appraise and apply information in all forms to manage health in daily life in terms of healthcare, disease prevention and health promotion.

With the new opportunities in technologies and e-health health literacy as an essential skill for the 21st century is becoming even more important in order for people to navigate the information available at e.g. the internet and from health systems.

The presentation introduces the results of the European health literacy project to set the scene for further discussions on how to improve the health literacy of European populations and the accessibility of systems with the use of new technologies. More information can be found at www.healthliteracyeurope.net.
Roberto Bertollini, World Health Organisation (WHO)

Dr Roberto Bertollini is the chief scientist and World Health Organisation (WHO) Representative to the European Union, working to enrich the overall WHO strategic partnership with the European Union in global health, development policy, humanitarian action, and research and health policy. Dr Bertollini holds a degree in medicine and a postgraduate degree in paediatrics, as well as a master’s degree in public health from the Johns Hopkins University in the USA.

In addition to his position as WHO Representative to the European Union, Dr Bertollini is chief scientist with the specific task of supporting the Regional Director’s Office with the scientific evidence that underpins WHO health policies and strategies. From 2007-2010, Dr Bertollini was coordinator of evidence and policy for the environment and health at WHO headquarters having previously served from 2000-2007 as a technical director at WHO/Europe.

Before this he was the founding director of the WHO European Centre for Environment and Health in Rome from 1993 to 2000. Dr Bertollini’s main professional interests concern the environmental influences on health, with special reference to the effects of emerging threats such as climate change as well as the use of epidemiology for public health policy development and the evaluation of public health programmes and practices.

Key message

Literacy and health literacy are fundamental components of pursuing health and well-being in modern society. As societies grow more complex, people are increasingly bombarded with health information, misinformation and complex health care systems. Becoming a health-literate person has become a growing challenge.

At the same time, we now understand that poor health literacy adversely affects people’s health. Nevertheless, it is a neglected area of public health action and research. Within this framework, WHO disseminates information about actions taken by public health as well as other sectorial authorities and stakeholders to strengthen people’s health literacy.

Health literacy is both a means and an outcome of actions aimed at promoting the empowerment and participation of people in their communities and in their health care. Health literacy provides a unique opportunity for the health-related organizations and professionals to improve population health and to affirm their leadership capacity.
Kaisa Immonen-Charalambous, European Patients’ Forum (EPF)

Kaisa Immonen-Charalambous is senior policy adviser at the European Patients’ Forum (EPF), having joined the organisation in 2010. She has a Master’s degree in International Relations (UK and Finland). She is responsible for the overall lead of EPF’s policy and advocacy work at EU level, including policy analysis, liaising with the EU institutions and stakeholders; and developing EPF’s policy positions in consultation with the membership.

Specific areas of responsibility include patient empowerment and patient-centred chronic disease care; quality and safety of healthcare; health literacy; clinical trials; pharmaceuticals regulation; and cross-border healthcare.

She is a member of the European Commission’s expert group on patient safety and quality of care, the European Medicines Agency’s Working Party with Patients and Consumers, and the PISCE Platform of Experts on Self-Care. Before joining EPF she worked in EU health policy, advocacy and external communications roles in both the private and NGO sectors.

The European Patients’ Forum is a not-for-profit, independent umbrella organisation of patients’ organisations in the EU, currently with 65 member organisations active in public health and health advocacy. Its mission is to ensure that the patients’ community drives policies and programmes that affect patients’ lives, to bring the changes needed to empower them to be equal citizens in the EU.

Key message

Chronic disease requires a fundamental shift from a disease-centred to a patient- and family-centred approach, combining self-management with well-integrated professional support. This implies the need to empower patients and involve them at every level in the health system. Health literacy is a key aspect of empowerment: the knowledge and competence gained through health literacy leads to the strength and empowerment needed to manage well a disease and its impacts on quality of life.

Technology can provide self-management support and motivation to patients and carers, e.g. access to one’s own health information, tools for self-monitoring, support and motivation, and for connecting to other patients.

Technology in itself is not enough to empower; digital literacy, access issues and ethics of consent and privacy need to be addressed. Technology support needs to be co-designed with and for patients, and it needs to be embedded as part of an integrated care system, rather than an ‘ad-hoc add-on’.
Marc Lange, European Health Telematics Association (EHTEL)

Marc Lange is the secretary general of European Health Telematics Association (EHTEL). He has a master degree in law, option business and European law. He is managing European projects for the public sector since 1992.

Founded in 1999, EHTEL (the European Health Telematics Association) is a pan European multi-stakeholder forum providing a leadership and networking platform for European corporate, institutional and individual actors dedicated to the betterment of healthcare delivery through eHealth.

EHTEL’s today priority is about method and tools that enable those deploying eHealth in the field to assess the impact of the planned eHealth services and successfully deploy them on a large scale.

**Key message**

The large-scale deployment of connected health (i.e. telemedicine, e-health and m-health) can contribute to shifting medicine from reaction to prevention, increasing patient adherence to treatment, and improving quality of life while helping to control the overall cost of healthcare. Health literacy will in the same time benefit from and contribute to these developments. Pursuing these objectives implies re-designing healthcare services towards a focus on integrated care. With the sound support of ICT, it means to:
- Streamline the collaboration between all the actors in the health care system and enable them to better interact with social care workers;
- Intensify the use of disease management and prevention programmes through better patient screening;
- Transfer patients safely from an acute care environment to either their own homes or to a nursing home;
- Enrol patients as members of the care team and empower them to manage their own health and adhere to treatments better.

United4Health (www.united4health.eu) and Renewing Health (www.renewinghealth.eu), two EU-funded project provide good examples on how eHealth can contribute to the modernisation of the healthcare systems. In addition, some of the services deployed in these two projects to the benefit of persons with diabetes type II provide also a good example on how eHealth can contribute health literacy and how the benefits expected from eHealth also rely on health literacy. The presentation will provide examples from North Norway and South Karelia (Finland), Wales and Scotland (UK).
Inés Madurga, Pharmaceutical Group of the European Union (PGEU)

Inés Madurga is a pharmacist working at the General Pharmaceutical Council of Spain (member organisation of PGEU).

Her job at the Products and Services Department involves elaborating medicines information and working with databases and related IT applied to healthcare.

Previously, she worked at the Oxford Radcliffe Hospitals NHS Trust in Oxford (UK) completing a Certificate in Clinical Pharmacy (Cardiff University, UK).

Key message

Reading Patient Information Leaflets (PILs) can be a challenge sometimes, not only understanding the information about medicines, but also having access to it. This last problem is even greater in some groups of population such as the elderly, those visually impaired and those who have mobility difficulties. Technology in general and mobile applications in particular, can help to improve access to information on medical products.

‘Medicamento Accesible PLUS’ is a mobile application designed as a possible technology solution to access to PILs issue. The application was launched in February 2014 after a collaboration of ONCE Foundation (Spanish organisation for blind or visually impaired), Vodafone Spain Foundation, and the General Pharmaceutical Council of Spain. To have access to the information about a specific drug, the patient just takes a picture of the box of that particular medicine with their smartphone or tablet in which the application was previously installed.

That medicine information, elaborated by the General Pharmaceutical Council, is shown in a clear and concise way. Furthermore, the application was designed following the principles of “Design for All” and “Accessibility”. This means that a visually impaired patient will hear the PIL read by their mobile, for example; or that a person with mobility difficulties will find it easier to take a picture and use their mobile to read the leaflet, that to open a folded PIL; least but not last, the elderly will have both solutions at their reach.

Although the project initially did not include an impact on health literacy, these data shows promising impact on medicines information access at least.
Irina Dinca, European Centre for Disease Prevention and Control (ECDC)

Irina Dinca works as senior expert, at Public Health Capacity and Communication Unit of the European Centre for Diseases Control (ECDC), in Sweden. She is public health physician, with PhD in public health, and more than 20 year experience in capacity building, health promotion and health policy.

Her current focus is on communicable diseases (CDs) such as: vaccine preventable diseases (VPD), HIV/AIDS/STIs, and Tuberculosis and on youth and under-served population groups; use of innovative approaches such as social marketing in improving health communication; bridge the gap between CDs and NCDs in the area of successful prevention interventions.

Dr. Dinca worked for John Snow, Inc. on a large-scale program on sexual and reproductive health (SRH) in Romania and Eastern Europe being responsible for policy and behavior change areas. At present, she is working on different projects, such as: communication for primary healthcare professionals around vaccination; study on vaccine hesitancy and options for interventions; capacity building on tuberculosis for high priority EU Member States; prevention of STI/HIV among young people and risk communication.

She also coordinated health promotion activities in Romania, including health promoting schools project. She set up a non-governmental organization in 1991 on delivering sexual and reproductive health education for young people.

Key message

In today's society we are facing the great challenge of making choice through the abundance of information we are being exposed too. This is relevant for the area of public health, where, most of citizens have limited information.

Health literacy, a relatively new concept, is clearly linked with the general literacy skills but these do not necessarily equip a person to cope with the complexity of information and skills needed to make healthier choices. In the health arena today the greatest burden is represented by non-communicable diseases, such as cardiovascular diseases and cancers.

This presentation will include the definition of health literacy, explore its components but most importantly will provide with practical examples of health literacy interventions. It will include the justification why investing in health literacy is relevant and how technology could be instrumental in this. Finally, the presentation would list possible contributions to be made by different sectors of society, including policy makers, for discussion.
Dr Terje Peetso joined the Health and Wellbeing Unit in DG Communications Networks, Content and Technology (DG Connect) in 2011. Her main responsibilities are related to the coordination of the implementation of the eHealth Action Plan 2012–2020, the European Commission’s strategy to address barriers to the full use of digital solutions in Europe's as part of the Digital Agenda for Europe Initiative, as well as the overall coordination of the policy group in the Unit.

In 2014 she was the EU Fellow in the University of Southern California, USA, where her research focus was on the obstacles which hinder the introduction eHealth in healthcare systems.

Dr Peetso holds a diploma in medicine from the University of Tartu, Estonia and has been working in the European Commission since 2003, starting in the Risk Assessment Unit in DG Health and Consumers. In 2006 she became a policy officer in the area of tobacco control in the same DG.

**Key message**

If we want to make a change in our healthcare systems asking for citizens' active participation in managing their health and diseases we need health literate citizens. The WHO suggests that additional costs of limited health literacy range from 3-5% of the total health care cost per year.

Today, digital tools can play a very important role in improving health literacy. The EU eHealth Task Force May 2012 Report of the EU Task Force on eHealth (an expert group created by the European Commission to tackle eHealth) stresses the importance of health literacy and the eHealth Action Plan 2012–2020 underlines the importance of digital health literacy.

Following these two documents the Commission launched in 2014 the Eurobarometer on digital health literacy which results demonstrate that around six out of ten respondents have used the Internet to search for health related information within the last year.

The Eurobarometer indicates where more attention should be paid – establish trustworthy sources of health information bring Internet to everybody, improve digital skills. It also demonstrates that cooperation between different sectors – healthcare, education, employment, ICT – is required.
6. CLOSING REMARKS

Karin Kadenbach, MEP

Karin Kadenbach (born 19 April 1958 in Vienna) is an Austrian social democratic politician. She is Member of the European Parliament since 2009.

Within the Parliament, she is member of the Committee on Environment, Public Health and Food Safety, the Committee on Regional Development, the Committee on Agriculture as well as the Committee on Budgetary Control.

Furthermore Karin Kadenbach is Vice-President of the Delegation for relations with Japan and substitute Member in the Delegation for relations with the Korean Peninsula.

Prior to joining the European Parliament in 2009, Ms. Kadenbach served for sixteen years as municipal councillor in her municipality Großmugl and was a member of the Lower Austrian Regional Assembly for seven years.

From 2007 to 2008, she was regional minister, holding the portfolio "Health and Nature Protection" in the Lower Austrian Regional Assembly. After graduating in Advertising and Marketing at Vienna University of Economics and Business, she worked at J. W. Thompson advertising agency.

Karin Kadenbach lives in Großmugl and Brussels and is a mother of five children.
7. THE HEALTH LITERACY PLATFORM

The Standing Committee of European Doctors (CPME), the European Patients’ Forum (EPF), Maastricht University, the Pharmaceutical Group of the European Union (PGEU) and Merck-Sharp & Dohme (MSD) have joined forces in a collaborative network in 2011 to support a better understanding of health literacy among policymakers and key stakeholders, and highlight its value for individuals, healthcare systems and society.

The platform sees health literacy as a topic of critical importance across sectors. Since its establishment in 2011, it has been engaging with the European Parliament and the European Commission to explore ways to promote better health education, and more empowered and knowledgeable European citizens, as a means to improve overall health outcomes in Europe.

Beyond its ongoing dialogue with EU policymakers, the topic of health literacy has also been presented in dedicated workshops at the European Health Forum Gastein for the past 4 years.

A number of collaborative research and advocacy projects amongst public health experts are being undertaken to provide evidence for the need to improve health literacy, and to explore the potential channels to do so.

This collaborative network is dedicated to making health literacy a priority in Europe in the future, and to help place patients and citizens at the centre of healthcare systems.
8. STOA ADMINISTRATION

European Parliament
Scientific Foresight Unit (STOA)
Directorate-General for Parliamentary Research Services (DG EPRS)
European Parliament
Rue Wiertz 60
B-1047 Brussels
E-mail: stoa@europarl.europa.eu

Director-General - Directorate-General for Parliamentary Research Services
Anthony Teasdale

Acting Director, Directorate C, Impact Assessment & European Added Value
Joseph Dunne

Head of Unit - Scientific Foresight Unit (STOA)
Theo Karapiperis

Head of Service - STOA Secretariat
Zsolt Pataki

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Gianluca Quaglio – Seconded National Expert

Assistants
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Damir Plese
Anne Villers

Trainees
Sara Cagol
Guillermo Garrido-Lestache