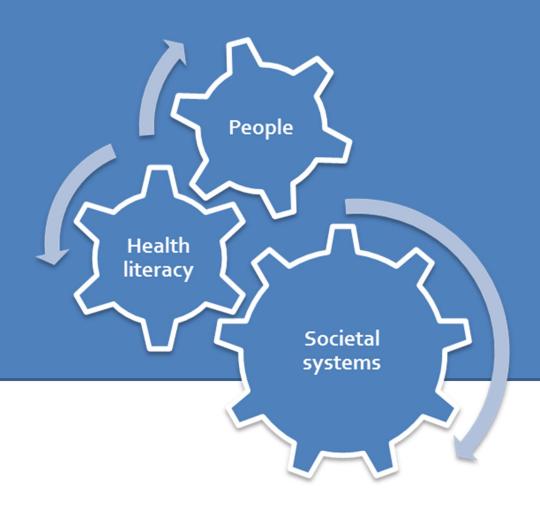
# HEALTH LITERACY IS A POLITICAL CHOICE

A health literacy guide for politicians

Kristine Sørensen







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Kristine Sørensen Global Health Literacy Academy

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Health literacy is closely linked to literacy and entails the knowledge, motivation and competency to access, understand, appraise and apply information to form judgement and make decision concerning healthcare, disease prevention and health promotion to maintain and promote quality of life during the life course.

– The European Health Literacy Consortium

#### **FOREWORD**

The role of politicians in advancing health literacy is crucial. However, health literacy is a relatively new concept in the political arena and not everyone has a full understanding of its meaning and why it matters. This health literacy guide, therefore, aims to inform politicians about health literacy and its impact on public health; its relevance as a political asset for public good; and the importance of health literacy and cross-sectoral partnerships for building coalitions to implement health literacy in policy and strategies.

Recognizing the work load of politicians the guide is deliberately made short and concise to facilitate easily and quickly reading. More inspiration and details can be found in the reference list from which the content of the health literacy quide is drawn.

Health literacy is a challenge for almost one in two. To bridge the gap related to health literacy disparity politicians are needed who can act as champions and ambassadors for raising awareness and implementing health literacy as part of health policy making locally, regionally, nationally and internationally.

Political health literacy leadership is vital for the creation of health literate societies; and with this guide politicians are encouraged to become health literacy trailblazers paving the way for others to follow them on this specific policy mission. Hopefully, this health literacy guide can initiate the spark to facilitate the impact of making health literacy the political choice towards an inclusive and sustainable society where no one is left behind.

Kristine Sørensen

Global Health Literacy Academy

December 2016

We need health literacy at the political level, in the interest of policy coherence spanning multiple sectors.

– Margaret Chan

#### INTRODUCTION

The health and well-being of a population are vital contributors to the social and economic development of societies. However, recent studies have revealed that larger parts of many populations across the world face problems in accessing, understanding, appraising and applying information to manage their health. Recognizing that health literacy is detrimental to health outcomes the current disparity related to limited health literacy is a public health challenge that cannot be neglected.

Hence, to build a health literate society, we need a health literate public, health literate health professionals, and health literate politicians and policy-makers (1). It requires collective efforts from all stakeholders in policy, research, education and practice to bridge the gap. This brief guide is designed for politicians wishing to know more about health literacy and how to play an active role in health literacy advocacy and policy-making.

Policy making involves deliberation among individuals, communities and organizations on solutions for public problems, each contributing their own perspective and evidence while debating about values, ideas and priorities towards either reaching a consensus or marshalling a majority of votes (2). Essentially, politics is all about preparing and implementing strategies to achieve certain goals. Politics is a way of achieving a given goal, and the political debate is spent deciding which goals to strive for. In the end, voters will judge parties and politicians by the concrete results they have achieved, not by the promises they made.

Yet, why engage in the advancement of health literacy as a political goal? Clearly, politicians are encouraged to engage in health literacy for four reasons: it is evident, it is measurable, it is feasible and it has an inspirational value for public good (3).

Health literacy, evidently, is closely linked to literacy and entails the knowledge, motivation and competency to access, understand, appraise and apply information to form judgement and make decision concerning healthcare, disease prevention and health promotion to maintain and promote quality of life during the life course. Whereas literacy refers to basic skills needed to succeed in society, health literacy requires additional skills, including those necessary for finding, evaluating, and integrating health information from a variety of contexts. Health literacy is important when managing health and for interacting with healthcare services and social systems. In turn, services and organizations need to be designed in a health literacy friendly way to enhance collective efforts and better health outcomes for the individual and society as a whole (4).

Health literacy can be measured at individual and population level by using various kinds of tools. Screening tools applied in clinical settings revealed worse outcomes for patients with poor health literacy levels than for patients with higher levels of health literacy (5). Population studies such as the European Health Literacy Survey indicated that almost one in two face difficulties in managing own health and navigating systems (6). Screening and monitoring health literacy will enlarge the evidence base to support decision-makers and practitioners to qualify planning and daily practice.

Overcoming barriers of health literacy is feasible as initiatives can be linked to, for example, quality standards for healthcare, health system performance measures, organizational audits, behavioural change programmes and self-management programmes. Activities can include, for example, focus

on plain language and simplicity in communication, cultural awareness, personalised treatment, availability of choice, and navigation support.

Health literacy is an inspirational value for the public good. Health literacy is closely linked to empowerment and the investment in health literacy is an ethical imperative to bridge inequality (7). Notably, improving health literacy in populations provides the foundation on which citizens are enabled to play an active role in improving their own health, engage successfully with community action for health, and push governments to meet their responsibilities in addressing health and health equity. Meeting the health literacy needs of the most disadvantaged and marginalized societies will particularly accelerate progress in reducing inequities in health and beyond (8).

Essentially, health literacy concerns the ability to make sound health decision in the context of everyday life – at home, in the community, at the workplace, the health care system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility (1). Health literacy, therefore, need to be taken into account by politicians when developing public health as the science and art of preventing disease, prolonging life and promoting health through the organized efforts and informed choices of society, organizations, public and private, communities and individuals (9).



#### THE IMPACT OF HEALTH LITERACY

The concept of health literacy was first coined in the 1970s, however, it was not until the 1990s that interest in health literacy began increasing dramatically. The conceptual model outlined in Figure 1 describes the pathway associated to health literacy in more detail (4).

The core refers to the knowledge, motivation and competencies of accessing, understanding, appraising and applying information to form judgment and make decisions concerning healthcare, disease prevention and health promotion. Essentially, (1) Access refers to the ability to seek, find and obtain health information; (2) Understand refers to the ability to comprehend the health information that is accessed; (3) Appraise describes the ability to interpret, filter, judge and evaluate the health information that has been accessed; and (4) Apply refers to the ability to communicate and use the information to make a decision to maintain and improve health.

Each of these competencies represents a crucial dimension of health literacy, requires specific cognitive qualities and depends on the quality of the information provided: obtaining and accessing health information depends on understanding, timing and trustworthiness; understanding the information depends on expectations, perceived utility, individualization of outcomes, and interpretation of causalities; processing and appraisal of the information depends on the complexity, jargon and partial understandings of the information; and effective communication depends on comprehension. The competencies also incorporate the qualities of functional, interactive and critical health literacy (10) and highlights the need of systems, organizations and services to be health literate to co-facilitate the process (11).

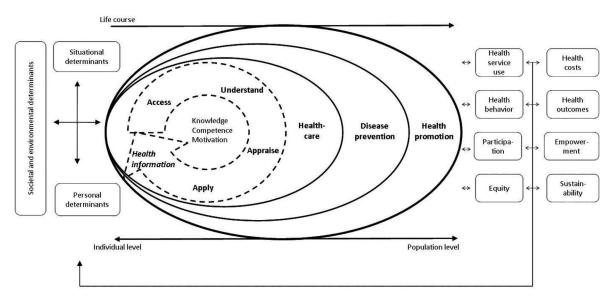


Figure 1: The influential factors and outcomes of health literacy (4)

As contextual demands change over time, and the capacity to navigate the health system depends on cognitive and psychosocial development as well as on previous and current experiences, the skills and competencies of health literacy develop during the life course and are linked to life-long learning.

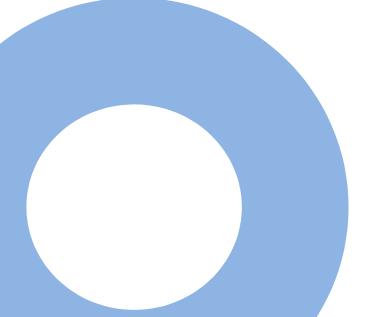
Health literacy is influenced by personal, situational and societal and environmental determinants. The personal determinants include, for example, age, gender, race, socioeconomic status, education, occupation, employment, income, and literacy. The situational determinants entail, for example, social support, family and peer influences, media use and physical environment. Lastly, the societal and environmental determinants can be described, for example, as the demographic situation, culture, language, political forces and societal systems.

Health literacy, in turn, impacts health behavior and the use of health services, and thereby will also impact on health outcomes and on the health costs in society. At an individual level, ineffective communication due to poor health literacy will result in errors, poor quality, and risks to patient safety of the healthcare services. At a population level, health literate persons are able to participate in the ongoing public and private dialogues about health, medicine, scientific knowledge and cultural beliefs and are being empowered to form judgement and make decisions to manage their health. Essentially, the benefits of health literacy impact the full range of life's activities - home, work, society and culture playing a vital role for people's equity and sustainability in life.

Health literacy is strongly associated with educational attainment, as well as with basic literacy that affects a wide range of cognitive, behavioral, and societal skills and abilities. Notably, health literacy can be distinguished from other type of literacies, such as *science literacy* that refers to the ability to comprehend technical complexity, understanding of common technology, *cultural literacy* that includes recognizing and using collective beliefs, customs, world-views, and social identity relationships and *civic literacy*, which concerns knowledge about sources of information and about agendas and how to interpret them, enabling citizens to engage in dialogue and decision-making.

Often a distinction is made between functional, interactive and critical health literacy. Functional health literacy refers to the ability of applying basic literacy skills in health situations; interactive health literacy includes the ability to apply more advanced cognitive and literacy skills to make decisions in health; and critical health literacy refers to the ability of being able to critically analyse health situations to make decisions and interact accordingly (10).

Essentially, rooted in contemporary health promotion health literacy is regarded as an asset - a set of capacities that enable individuals to exert greater control over their health and the range of personal, social and environmental determinants of health.



#### **HEALTH LITERACY - A POLITICAL CHALLENGE FOR PUBLIC HEALTH**

Several aspects highlight the need for political engagement in the health literacy challenge:

- 1. The large numbers of people affected: Health literacy surveys have revealed health literacy to be a public health challenge, rather than a problem for the few. The European Health Literacy Survey, for example, revealed that 1/3-2/3 in populations was affected depending on the country studied (12).
- 2. **Poor health outcomes:** Studies demonstrate that persons with limited health literacy skills are significantly more likely than persons with adequate health literacy skills to report their health as poor (13).
- 3. **Increasing rates of chronic disease:** The burden of chronic diseases is rapidly increasing worldwide. It has been calculated that, in 2001, chronic diseases contributed approximately 60% of the 56.5 million total reported deaths in the world and approximately 46% of the global burden of disease (1). The proportion of the burden of Non Communicable Diseases is expected to increase to 57% by 2020 (14). Health literacy plays a crucial role in chronic disease self-management, for example, diabetes self-management (15).
- 4. **Health care costs:** Persons with limited health literacy skills make greater use of services designed to treat complications of disease and less use of services designed to prevent complications. Studies demonstrate a higher rate of hospitalization and use of emergency services among patients with limited health literacy skills. This higher use is associated with higher healthcare costs (16).
- 5. **Health information demands:** According to a *Eurobarometer* survey a large number of Europeans are unaware that antibiotics are ineffective against viruses (57%), colds and flus (44%) (17). This lack of appropriate and actionable knowledge, or in other words, the lack of health literacy, may affect the interaction between doctor and patient, joint clinical decision making, the effectiveness of treatment and the patient experience. In the worst case scenario this lack of health literacy may result in unrealistic expectations, incorrect decisions, ineffective therapies, poor outcomes and patient dissatisfaction (17).
- 6. **Equity:** Limited health literacy follows a social gradient and can further reinforce existing inequalities. People with limited health literacy most often have lower levels of education, are older adults, are migrants and depend on various forms of public transfer payments (18).

### The vision is to develop health literacy for the people, by the people and shared with the people.

– International Health Literacy Association

### HEALTH LITERACY – A POLICY ASSET FOR HEALTHY SOCIETIES WORLDWIDE

In order to bridge the health literacy gap health literacy as an asset for public health has increasingly become a topic on policy agendas worldwide. Markedly, health literacy promotes empowerment, which in turn is vital for achieving, for example, the internationally agreed health and development goals as well as the emerging threats such as from the pandemic influenza, climate change and non-communicable diseases. Although, there is no specific target on health literacy within the Sustainable Development Goals (SDGs) of the United Nations, efforts to advance health literacy will be crucial in whether the social, economic and environmental ambitions of the 2030 Agenda for Sustainable Development can be achieved (19). In the following international and national health literacy policy examples are provided to foster inspiration and action.

#### International health literacy policies

Members of the **United Nations Economic and Social Council** has agreed that health literacy – the ability to gain access to, understand and use health information for promoting and maintaining good health – is an important factor in the overall public health of a country. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to significantly increase the effectiveness of health care programmes and treatment. The Council provided a clear mandate for action in 2009 stressing that "health literacy is an important factor in ensuring significant health outcomes and in this regard, call for the development of appropriate action plans to promote health literacy" (20).

The World Health Organization indicates as societies grow more complex and people are increasingly bombarded with health information and misinformation that health literacy becomes essential. People with strong health literacy skills enjoy better health and well-being, while those with weaker skills tend to engage in riskier behaviour and have poorer health. With evidence from the recent European Health Literacy Survey, the report Health Literacy - Solid Facts identifies practical and effective ways public health and other sector authorities and advocates can strengthen health literacy in a variety of settings, including educational settings, workplaces, marketplaces, health systems, new and traditional media and political arenas. The report can be used as a tool for spreading awareness, stimulating debate and research and, above all, for informing policy development and action (18). Furthermore, the European Regional Office of the World Health Organization recommends in their policy strategy **Health 2020** that health promotion programmes based on principles of engagement and empowerment, including improved health literacy, can offer real benefits for increasing population health (21). In addition, the Regional Office for South-East Asia has produced information sheets on Optimizing Health Literacy introducing health literacy, its relevance to public policy, and the ways it can be used to inform the promotion of good health, the prevention and management of communicable and non-communicable diseases, and the reduction of health inequities. It provides information assisting organizations and governments to incorporate health literacy responses into practice, service delivery systems, and policy, especially for low- and middle-income countries (22). According to the World Health Organization's Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development health literacy empowers and drives equity as health literacy is founded on inclusive and equitable access to quality education and life-long learning. Hence, governments have

committed themselves to recognize health literacy as a critical determinant of health and to invest in its development (19).

The EU's European Commission has pointed out the necessity for policy efforts at the EU level as well as fundamental principles and values for actions on health. Citizens' empowerment is highlighted as a core value because healthcare is becoming increasingly patient-centred and individualized, with the patient becoming an active subject rather than an object of healthcare indicating that community health policy must take citizens' and patients' rights as a key starting point based on participation in and influence on decision making as well as competences needed for well-being including health literacy (23). The Vilnius Declaration: sustainable health systems for inclusive growth in Europe agreed to by health ministers during the Lithuanian Presidency of the Council of the European Union calls on European governments and the EU to take immediate action to increase investment in health promotion and disease prevention through for example more investment in primary, secondary and tertiary prevention as well as health literacy (24). The Riga Roadmap: investing in health and wellbeing launched by the Latvian Presidency of the Council of the EU in 2015 highlights the need for developing an effective health promotion and disease prevention agenda. It calls to strengthening the role of healthcare professionals, recognizing that healthcare workers play an indispensable role in educating patients and promoting health literacy, particularly in education and workplace settings. Furthermore, it is recommended to monitor health literacy across all the European Unions' Member States by the use of the European Health Literacy Survey (HLS-EU) to collect comparative data for further investment in health literacy interventions (25).

#### National health literacy policies

At national policy levels several countries have taken the lead in developing health literacy policies, strategies and guidelines to promote and qualify health literacy.

#### **United States of America**

The government of the **United States of America** launched the National Action Plan to Improve Health Literacy in 2010 (26). The Action Plan seeks to engage organizations, professionals, policymakers, communities, individuals, and families in a linked, multi-sector effort to improve health literacy and it is based on 2 core principles:

- All people have the right to health information that helps them make informed decisions.
- Health services should be delivered in ways that are easy to understand and that improve health, longevity, and quality of life.

The Action Plan contains 7 goals that will improve health literacy and strategies for achieving them:

- 1. Develop and disseminate health and safety information that is accurate, accessible, and actionable
- 2. Promote changes in the health care system that improve health information, communication, informed decision-making, and access to health services
- 3. Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in child care and education through the university level
- 4. Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community

- 5. Build partnerships, develop guidance, and change policies
- 6. Increase basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy
- 7. Increase the dissemination and use of evidence-based health literacy practices and interventions

Through focus on health literacy and collective efforts the aim is to improve the accessibility, quality, and safety of health care; reduce costs; and improve the health and quality of life of millions of people in the United States (26).

Notably, Koh, who has been involved as politician and official in the policy administration in the United States, explains why health literacy became a priority on the American health agenda:

"The time is right to accelerate our national commitment to providing the American people with clear, understandable, and actionable science-based health information. The promises of medical research, health information technology, and advances in health care coverage and delivery can be realized only if our nation addresses the challenge of limited health literacy. The federal initiatives of the past few years, combined with a growing commitment to encouraging health-literate organizations and system change, can help the nation tackle health literacy and ultimately help us all lead longer, healthier lives" (27).

#### China

In 2008, a public notice was released concerning Health Literacy for Chinese citizens — Basic Knowledge and Skills, which explicitly put forward a total of 66 goals for basic health knowledge, behaviour and skills that urban and rural residents should have for maintaining and promoting their health. The notice is known as Health Literacy 66 and it was one of the first government documents in the world to define the public health literacy. It is based on the evaluation of risk factors of major health problems among the urban and rural residents and implemented to reduce infectious disease occurrence and curb the rising trend of chronic disease (28).

#### New Zealand

The Ministry of Health in **New Zealand** designed "A Framework for Health Literacy" because the way health systems are organised, individuals and whānau can often face a series of demands on their health literacy which includes the capacity to obtain, process and understand basic health information and services in order to make informed health decisions (29).

According to the Ministry of Health a health-literate health system **reduces** these demands on people and **builds** health literacy skills of its workforce, and the individuals and whānau who use its services. It provides high-quality services that are easy to access and navigate and gives clear and relevant health messages so that everyone living in New Zealand can effectively manage their own health, keep well and live well. The Ministry of Health developed the framework because it is committed to a health system that enables everyone living in New Zealand to live well and keep well. Regarding health literacy advancement an important part of this, the framework outlines expectations for the health system, health organizations and the entire health workforce to take action that:

- Supports a 'culture shift' so that health literacy is core business at all levels of the health system.
- Reduces health literacy demands and recognises that good health literacy practice contributes to improved health outcomes and reduced health costs.

To implement the framework in the health system, it is necessary to build leadership and knowledge of health literacy approaches. Only in this way, the health system can make the long-term and sustainable changes needed to become health literate. The framework also identifies some success indicators that individuals and whānau can expect to see from every point of contact with the health system (29).

#### Singapore

The vision for a health literate **Singapore** is a nation where people can find, understand and use information and services that will guide them in making informed health decisions that enhance their guality of life. The goals include:

- To put in place an infrastructure that supports the core elements necessary to lead, coordinate, build capacity and evaluate health literacy initiatives, services and policies in Singapore
- To enhance the health status and quality of life of the people in Singapore by putting in place health literacy initiatives that influence individuals, providers and systems.

The priority actions for implementation include to

- Incorporate health literacy improvement in mission, planning and evaluation.
- Support health literacy research, evaluation, training and practice.
- Conduct formative, process and outcome evaluation to design and assess materials, messages and resources.
- Enhance dissemination of timely, accurate and appropriate health information to health professionals and the public –Plain Language Guidelines.
- Design health literacy improvements to healthcare and public health systems that enhance access to health services.

Hence the Health Promotion Board in Singapore has focused on developing a Plain Language Guide; developing a tool to establish a baseline and measure levels of health literacy and setting up a multiagency committee on Health Literacy with partners across the Government.

#### Austria

In 2012 The Ministry of Health in **Austria** decided upon ten new health targets. One of these targets involved strengthening health literacy in the population and specifically to empower patients and to design target-group specific health information that improve health literacy. The 10 Austrian health targets were developed with the aim to prolong the healthy life years of all people living in Austria in the coming 20 years (until 2032), irrespective of their level of education, income or personal living condition. Since population health is profoundly influenced and determined by many sectors outside the health care sector, the Austrian health targets were defined in a broad and participatory process that involved more than 40 stakeholders from relevant institutions and civil society. Notably, the health targets are to be implemented with short- and mid-term as well as long term

objectives at national and regional level in agreement with the respective national and regional governments as well as the main insurance association(30).

#### **Scotland**

The government of **Scotland** developed "Making it Easy - A health Literacy Action Plan for Scotland" which was launched in 2014 (31). The Scottish Action Plan

- Highlights the hidden problem of low health literacy and the impact that this has on our ability to access, understand, engage and participate in our health and social care.
- Explains that low health literacy leads to poor health outcomes and widens health inequality.
- Calls for all of us involved in health and social care to systematically address health literacy as a priority in our efforts to improve health and reduce health inequalities.
- Sets out an ambition for all of us in Scotland to have the confidence, knowledge, understanding and skills we need to live well, with any health condition we have.
- Lays out the actions the Scottish Government and partners are taking to help all of us in health and social care collaborate and help realise this ambition.

Generally, familiarity with the concept of health literacy, financial incentives, the involvement of stakeholders, the organization of the health care system within a country, conceptions of citizens' rights all set the boundaries for the possibilities to develop policies and organise activities to improve health literacy. For example, in countries with strong non-governmental organizations such as the National Adult Literacy Association in Ireland or in countries were national working groups with many stakeholders are active, implementations of activities and initiatives to improve health literacy run more effortless (32). At EU level a coalition of stakeholders representing academia, health professionals, patients and industry has continuously stimulated the debate on making health literacy part of EU policy (33). In the United States the Centres of Disease Control and Prevention has played an active role in executing the intentions of the health literacy policy stated in the American national action plan on health literacy through, for example, dissemination of material and capacity building (34).

If we want health equity, we need to make health literacy a priority.

– Sylvia Mathews Burwell

#### **GLOBAL PARTNERSHIPS FOR HEALTH LITERACY**

Politicians, professionals, civil society and the private sector can all contribute to addressing health literacy challenges. Many actors, agencies and settings are actively promoting, developing and implementing health literacy initiatives. Some countries have health literacy networks, coalitions and alliance and often these have been strategically established alongside organizations that support patient empowerment and health promotion. Professional organizations and civil society organizations that promote patient participation, public health and consumer rights are also important advocates for health literacy. The private sector can make significant contributions. Corporate social responsibility can include providing reliable information to patients and consumers, as should all health reporting, marketing and advertising. In particular, the mass media and the information and communication industry can work with patients and consumers to contribute to better information, experience exchange and transparency (18). Inter-sectoral approaches are recommended and partnerships can be made involving a variety of stakeholders with a wide range of roles and jurisdictions. Their objectives and initiatives concerning how to advance health literacy may be unfold as outlined below (8):

**Government** – develop policies and plans on health literacy promotion, including sustained funding, systematic intervention and surveillance; work across sectors for win-wins and meet obligations to provide people with accurate, up to date information that is unbiased by undue influence from inside and outside the health sector.

**Civil society** – work together to bring different expertise, experiences and capacities to bear in community-based communication and health literacy efforts in all kinds of settings throughout the life course.

**Media** (including social media) – serve as a critical platform for health literacy messaging, harnessing the idealism and enthusiasm of youth, and meeting an ethical threshold for accuracy to support, rather than subvert, people's right to health.

**Community partners** – provide local solutions to the health literacy problem by initiating initiatives to overcome barriers in communication and navigation with health and social services; adult literacy courses and health promotion activities.

**Research and academic institutions** – develop and improve methods to measure health literacy, collate and distribute examples of best practice in health literacy intervention development, and provide evidence of what works, in which contexts, and why.

**Business partners** – enhance health literacy at the work place and among customers and clients through investment in corporate social responsibility with regards to people, planet and profit.

#### Health literacy networks and interest groups

There is a growing vibrant health literacy community. In recent years, specific networks advocating for health literacy have been established worldwide. They constitute formal and informal national, regional and international platforms for knowledge exchange and capacity building.

Internationally, the **Global Working Group on Health Literacy** of the International Union of Health Promotion and Education (IUHPE) has advocated for health literacy since 2010 with the aim to initiate and support action, policy and research on health literacy, acknowledging the contribution of health literacy to reducing disparities in the promotion of health and wellbeing, and sustainable development, and to the pursuit of equity within and between countries, in the global context (35).

In 2016 a three step launch was made in Geneva, Washington and Haiphong to inaugurate the **International Health Literacy Association** (IHLA). The International Health Literacy Association aims to stimulate and disseminate health literacy research and best practice, promote health literacy continuing education and professional development and advocate for health literacy raising awareness worldwide.

Regionally, **Health Literacy Europe** was established in 2010. It is a network for researchers and professionals involved in improving the field of European Health Literacy. The network provides a platform for interaction with colleagues from different parts of Europe and abroad. Health Literacy Europe organizes conferences, which gather health literacy experts to share their knowledge and learn from colleagues with multi-disciplinary backgrounds. Health Literacy Europe also supports other national, regional networks inside and outside Europe to promote health literacy in research, policy and practice.

The **Asian Health Literacy Association** was launched in 2013. Inspired by the European Health Literacy project a group of Asian countries was formed to manifest health literacy in Asia and to measure health literacy in Asian populations. Several conferences have been organised in Taiwan and Vietnam to share the results and impact.

Sub-regionally, the **Nordic Health Literacy Network** has gathered researchers and practitioners to stimulate and foster health literacy in the Nordic countries: Denmark, Finland, Iceland, Norway, and Sweden. Furthermore, groups sharing the same language collaborate such as the German speaking countries (Austria, Germany, and Switzerland); and the French speaking countries (Belgium, France and Luxembourg) as well as the Portuguese speaking countries of Portugal and Brazil.

Nationally and state wide, networks and interest groups have increasingly been formed in the United States, Canada and Europe. These include among others **Health Literacy Missouri**, **BC Health Literacy Network**, the **UK Health Literacy Network**, the **Dutch Health Literacy Alliance**, the **Austrian Health Literacy Platform** and **the Danish Health Literacy Network**.

#### Health literacy awards

An activity where politicians are often involved relates to the launch of health literacy awards. Health literacy awards with the aim of rewarding outstanding health literacy projects and initiatives have been established in several countries.

The National Health Literacy Innovator Award is an American national contest to reward innovators in health literacy, seeking the nation's best health literacy practices in print, in practice, and in the media. It is an open competition for any company, organization or individual that can demonstrate excellence in health literacy in one of the three contest categories. The Award is provided by Health Literacy Innovations, HLI, founded to create tools to help eliminate medical mistakes and confusion due to low health literacy (36).

Health Literacy Missouri established the *Cecilia and Leonard Doak Health Literacy Champion Award* to honor individuals and organizations who make outstanding contributions in health literacy and whose work focuses on bridging the gap between the skills of people and the demands of the health care system. The award, named after the founders of the health literacy movement, is presented to a single individual or organization each year and recognizes those who exhibit the highest standards of excellence, dedication and accomplishment over a sustained period of time, and who are creative and highly skilled pioneers in the health literacy field. The award recognizes rigorous work and celebrates collaborative efforts to shape a path to good health (37).

The Crystal Clear Awards in Ireland is a partnership between MSD and NALA, the National Adult Literacy Agency, with representation on the judging panel from the Health Service Executive (HSE), the Health Information and Quality Authority (HIQA), UCD, a General Practitioner, NALA, and Trinity College, Dublin (38). The award is handed out to projects that are helping patients to take a more active role in the management of their own lifestyle, condition or illness and to make informed decisions about their own health. Four out of ten people in Ireland have trouble with health literacy and can have difficulty understanding health information. The many excellent initiatives that have been lined up for the awards help patients to have a better understanding of their health (39).

In **Belgium** the *Well Done MSD Health Literacy Awards* competition aims to stimulate best practice-sharing in order to empower patients, optimize the communication between healthcare professionals and patients and ultimately to safeguard the sustainability of the healthcare system. Health care professionals and associations are encouraged to submit their disease management projects with real impact on patients' lives. The initiative was established since 2012 and builds on a collaboration entailing partners from 12 main healthcare organizations with a jury chaired by the country's health literacy expert (40).

Notably, politicians can support health literacy network and partnership building in multiple ways. A concrete policy action can be to mobilize a health literacy network and ensure financial support to its activities, if it does not already exist in a certain country or region. Furthermore, politicians can be engaged in health literacy awards, conferences, national and regional strategy development processes and concrete policy making on health literacy issues, which demand and foster coalition building to succeed.

#### Health literacy in the media

Health literacy events, such as national health literacy conferences and health literacy awards often generate mentions and citations in the press and on social media. Politicians can contribute with statements to press releases and the social media before, during and after the events. Reference can be made, for example, to facts from existing health literacy data or the need for health literacy data; to patient narratives where health literacy played a significant role in the either positive or negative outcome of a service or treatment; and to the issue of generating equity in health and fairer outcomes for all. Politicians can also choose to participate in online discussions on Facebook, Twitter, LinkedIn and other kinds of social media. In addition, they can engage themselves with patient organizations and participate in online fora targeting people and patients with a specific disease or condition.

Health literacy is about rights, access and transparency. It is about a new form of health citizenship, in which citizens take both personal responsibility for health and become involved as citizens in social and political processes that address the root causes of health inequalities as well as inequalities in access to care.

– Ilona Kickbusch

#### THE IMPORTANCE OF POLITICAL LEADERSHIP

Politicians are constantly under immense pressure and at the same time they have to stay alert and informed to create a good impression in the media, interact with voters and leave their mark (3). Leaving their mark with regards to health literacy politicians can seek to

- Ensure that people, particularly, those who are most vulnerable in society are able to have their voice heard on health related issues that are important to them,
- Defend and safeguard people's health rights,
- Have their views and wishes genuinely considered when decisions are being made about their lives.

Believing that health literacy is central to the development of people-centred societies, essentially, health literacy advocacy and policy making is a process of supporting and enabling people to:

- Express their views and concerns regarding health and quality of life.
- Access health information and services.
- Defend and promote their rights and responsibilities in terms of health.
- Explore choices and options relevant for healthcare, disease prevention and health promotion.
- Design health literacy friendly environments at school, at the work place and other relevant settings.
- Create health literate organizations to facilitate better services.
- Support the development of health literate settings such as schools, work places, and communities.
- Educate the health related work force on health literacy.
- Ensure monitoring of health literacy.

Health literacy is a cornerstone in the development of 'healthy public policy' where healthy choices are made possible or easier for the citizens. All government sectors (including agriculture, trade, treasury, education, housing, transport and communications, for example) have roles in the creation and implementation of public policy and all should consider the health and equity consequences of their policy decisions (41).

Other critical strategies to better enable synergies in health and development planning will be to extend health literacy measurement beyond health-related reading ability and numeracy, building on recent attempts to develop valid and reliable tools that aim to more completely measure the broader health literacy concept in a range of populations which includes, for example, interaction with the health care system and critical appraisal of health information (8).

Besides, another key to success is the aim on providing access to information and technology including the Internet. The rapid expansion in access to new communications technology and use of social media offer new platforms for health literacy efforts such as through the use of E-Health and M-Health technologies. These can complement traditional platforms for health literacy, such as hospitals, health clinics, and schools, while harnessing the potential of using new settings: workplaces (health wellness programmes/public-private partnerships), places of worship, and other community settings (8).

## Addressing health literacy requires a whole-of-society approach.

– Zsuzsanna Jakab

#### GUIDE TO DEVELOP HEALTH LITERACY POLICY AND STRATEGY

To facilitate health literacy friendly communication it is useful for politicians to apply simple language, avoid jargon and ensure the content of policy messages to be accurate, accessible and actionable. Additionally, as health literacy is known to be content and context specific, policies ought to reflect the specific population needs and culture they are aimed at. Along these lines the approach for a Health Literate Canada, for example, includes explicit a vision, a mission and a set of values related to the advancement of health literacy in the country (42), where the values highlight that:

- Every person has an equal and inherent right to accurate, understandable, and culturally appropriate health information and services.
- Life-long learning is a fundamental ingredient for health literacy.
- Improving health literacy is a responsibility to be shared among multiple sectors.
- Creating opportunities for innovation and making use of all available evidence-informed strategies are both critical to success.
- The work will be approached with integrity and will uphold the honest, fair and respectful treatment of all people.
- Financial and social accountability is paramount at all times.

Notably, a starting point for politicians can be (42):

- To identify priorities and organize them into a comprehensive framework for improving health literacy in a certain country, region, city etc. incl. vision, mission and values.
- To recommend a set of actions to be taken at the national, provincial/territorial and local levels for the purpose of increasing health literacy among the population in a certain area.
- To facilitate conversations amongst practitioners, researchers and policy makers about health literacy and encourage cross-sectoral work around health literacy initiatives.
- To identify incentives and encouraging factors that can support the integration of health literacy into policy, practice, research and education.
- To evaluate and consistently monitor the progress of advancing health literacy.

Essentially, health literacy political priority areas can include to:

- Develop national and local strategies that strengthen health policy.
- Make standards for health literate organizations part of quality management and leadership.
- Adopt a multi-sectoral and multi-dimensional approach to building health literacy at all levels and in the various kinds of societal settings.



Health literacy – saves lives, saves time, saves money.

– National Institutes of Health

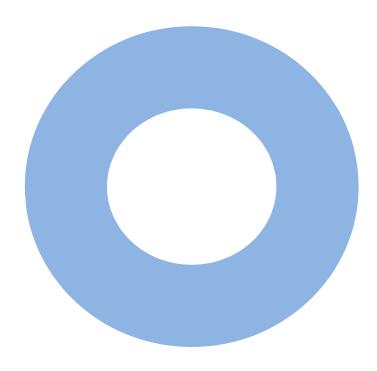
#### FACE THE CHALLENGE, BE THE CHANGE!

The strong social gradient related to health literacy and its close relation to quality of life and active participation in society call for a re-orientation of policy making focusing on the vision of 'well-being for all' that consider both individual well-being as well as societal and global well-being as a foundation of social cohesion that also extends to future generations (43). Leaving no one behind and bridging the gaps in health and human capabilities is imperative to achieving the goals of inclusive and sustainable development of society.

Addressing health literacy requires a whole-of-society approach. Many sectors and settings need to work together to improve health literacy of individuals and communities and to make environments easier to navigate in support of health and well-being (18). Hence, for societies to become health literate, all actors involved need to increase their health literacy (1):

- **Citizens** need to be making decisions about their health for themselves, not merely responding to decisions made for them by others;
- Patients need to be truly engaged and empowered to participate in care decisions;
- **Professionals** need to tailor their communication to meet the needs of their patients and see it as their responsibility to foster health literacy;
- **Politicians** need to incorporate the notion and paradigm of health literacy into their design of policy, their research agendas and their objectives for population health.

For the above vision to be a success; politicians are encouraged to become health literacy trailblazers and take the lead. Hopefully, this health literacy guide can help pave the way. It is time to create services and systems that meet people where they are. Essentially, the political goal regarding health literacy is evident, measurable, feasible and an inspirational value for public good. Indeed, health literacy is a political choice.



#### **ACKNOWLEDGEMENTS**

This health literacy guide for politicians explains in short what health literacy is about and why it matters. Building on examples of national and international health literacy policies it makes an introduction to how politicians can play an active role in the creation of health literate societies.

The thought of making this brief health literacy guide for politicians has been on my mind for several years due to many conversations with politicians, colleagues from the private and public sectors as well as practitioners and educators from the field who have all highlighted the need for a broader understanding of health literacy among politicians and policy makers involved in developing health literacy policy.

Knowledge transfer is essential for us to further develop the vibrant health literacy field and I hope with this guide to stimulate the policy conversation on health literacy. By shortly explaining what health literacy is and why it is important and highlighting existing health literacy policies to provide examples on how policy can be developed and executed in practice I hope to foster health literacy leadership among politicians and policy makers for them to take responsibility for facilitating the highly needed change. I wish the guide will help them succeed.

The health literacy guide for politicians is developed on the grounds of contributions from many colleagues, both explicitly and implicitly, and I thank all my colleagues involved in advancing health literacy across the globe as well as my family for providing support, feedback and food for thought throughout my health literacy journey.

Kristine Sørensen, December 2016

#### ABOUT THE AUTHOR

Kristine Sørensen PhD is the founding director of the Global Health Literacy Academy. As a thought leader she is committed to advance the global scope and scale of health literacy to improve health and quality of life for all. Her primary focus is to manifest health literacy in Europe and on the global agenda. Her educational background is in medicine, public health and global health diplomacy. She has acted as health literacy advisor for numerous organizations amongst others the European Commission, the World Health Organization, and Council of Europe. Kristine Sørensen and her colleagues in the HLS-EU European Health Literacy project (2009-2012) received the European Health Award 2012 for their societal impact. Kristine Sørensen is the focal point for Health Literacy Europe - a network for advancing European health literacy and founding member of the International Health Literacy Association, the Dutch Health Literacy Alliance (NL) and the Nordic Health Literacy Network as well as the Health Literacy Coalition in Brussels. She is member of the advisory boards of the Asian Health Literacy Association, Bridge4Health (CAN), Health Literacy for Children and Adolescence (DE) and GeWinn (DE) as well as of the EU expert panel ProSTEP on self-management. She is also appointed for the Board of Commissioners of Kindante responsible for 40 primary schools (NL) and active member of Rotary International.

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