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# NAVIGATING HEALTH



## THE ROLE OF HEALTH LITERACY

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# Health Literacy: a Call

We are living in a new health society (Kickbusch 2005). In almost every aspect of our lives, we are faced with questions and decisions about health. The sphere of health has expanded far beyond the confines of the health care system itself: health includes well-being and exercise; it involves what one eats and drinks, how one sleeps. It's discussed in fashion magazines and newspapers, on radio programmes and talk shows.

Policy documents ask us to become 'informed patients', 'engaged and active citizens' and 'empowered communities'. But most of us lack access to the necessary information and do not have the necessary skills to drive decisions for our health.

These skills are the essence of *health literacy*, defined as 'the ability to make sound health decisions in the context of everyday life.' At the 8th European Health Policy Forum in Bad Gastein in October 2005, a panel of international experts discussed the importance of building *health literacy* as a critical empowerment strategy for European citizens<sup>1</sup>. (Gastein Health Declaration 2005).



<sup>1</sup> The Healthy Choices Forum was chaired by Dr Ilona Kickbusch and Dr Hans Saan. Forum panelists included Dr Peggy McGuire, European Institute for Women's Health; Peter Kopelman, European Society for the Study of Obesity; Jaap Seidell, Free University Amsterdam; Ian Banks, European Men's Health Forum; Jurgen Pelikan, University of Vienna; Istvan Szilard, International Office for Migration, Budapest; Elke Thoss, Pro Familia; Per-G. Svensson, International Hospital Federation; Rolf Rosenbrock, Germany; Bosse Peterson, National Institute of Public Health, Sweden; Jonathan Berry, Health Improvement ContinYou, UK; Marianna Takki, European Commission. Rapporteurs were Daniela Maag and Suzanne Wait. The Forum was organised by Hans Stein, European Public Health Centre. The Forum and this report were made possible due to an unrestricted educational grant from Pfizer.

# to Action

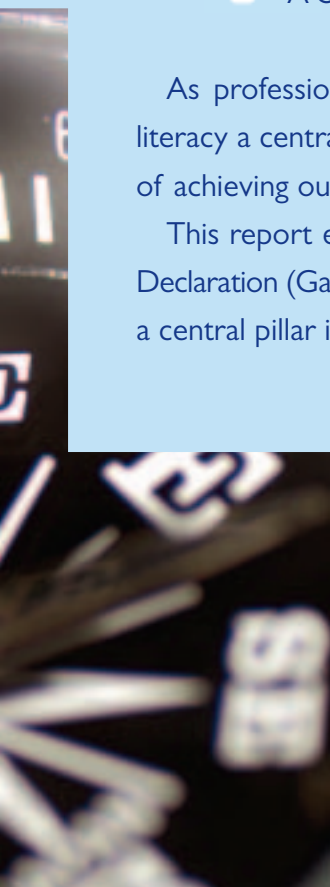
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## Why is health literacy so critical?

- ✓ **Health literacy is an essential life skill for *individuals*:**  
It may help individuals seek and use information and take control over their health.
- ✓ **Health literacy is a *public health* imperative:**  
building health literacy improves overall population health.
- ✓ **Health literacy is an essential part of *social capital*:**  
low health literacy is a strong contributor to health inequalities.
- ✓ **Health literacy is a critical *economic* issue:**  
A US study estimated that low health literacy costs the US economy 73 billion dollars per year.

As professionals and public health advocates, we urge Europe to lead the way in making health literacy a central pillar of its policies and actions. Without health literacy, we will undoubtedly fall short of achieving our goals for a healthy and prosperous European citizenship.

This report echoes the conclusions of the Healthy Choices forum, presented in the Gastein Health Declaration (Gastein Health Declaration, 2005). It is a Call to Action to policymakers to make health literacy a central pillar in health policy discussions, research and action at a European, national and local level.



## A. Introduction: Health literacy – the art of navigating

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The changing health environment carries mixed blessings for citizens making health decisions. On the one hand, there is more choice in treatment and more information to guide our choices. On the other hand, the deluge of information is often more confusing than helpful. Health care systems are becoming more complex and encompass a broader range of providers from different sectors than ever before. This rapidly-changing sphere of health demands a lot of us as patients and citizens.

Health decisions place us in a vulnerable position in which we must take risks without any certainty of outcome. This is true regardless of one's educational level, culture or social status. *Health literacy* is not a safeguard against this uncertainty. However, it may help us navigate health and health care with a better understanding of potential consequences: a map and a compass on a difficult and unpredictable journey.

Health literacy may serve as  
a map and a compass on  
what may be a **difficult** and

*unpredictable journey.*

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To navigate health, one needs...

### A here

understanding of one's current health state, socioeconomic and cultural values and context.



### A there

a clear sense of 'where we're going'. Why should I be healthy? Why should I be informed about my health? Every person's journey may be different, take more or less time, encounter different hurdles.



### A map

we need better information in a form that is digestible, meaningful and easy to interpret. Format is also important: not everyone is e-health literate, but paper also does not work for everyone.



### A compass

health professionals, publications, articles or the internet may serve as helpful guides.



### A path

we need messages about health that are accessible, appropriate to individual needs, cultural and social backgrounds.



### A friend

family and friends are essential in health, particularly as we get older. Health professionals, advocacy groups, community services – they may all help build our health literacy and provide a supportive environment for our health.

## B. What is health literacy?

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*Health Literacy is the ability to make sound health decisions in the context of every day life – at home, in the community, at the workplace, in 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.*

### I. The concept of ‘literacy’

Throughout history, in rich and poor countries alike, literacy has been recognised as ‘part and parcel of the pursuit of freedom, itself a central tenet of development’ (UNESCO 2003).

*‘Literacy levels, which are usually, but not always, related to levels of education, are important predictors of employment, active participation in the community and health status. They are also important predictors of the success of a nation.’*

(Health Canada, 2001)

Just as low literacy is linked to low health status, low health literacy contributes to socioeconomic disadvantage and may prevent individuals from fully engaging with society and achieving their life goals.

Health literacy is a building block to health and is a foundation for modern citizenship. It is a critical component of social capital and should be treated as such in policy debates – not just in health but across all sectors (Kawachi, 1999).





## 2. Health literacy skills are part of modern life skills

The WHO defines health literacy as ‘the cognitive and social skills and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’ (WHO 1998). Central to this notion is that of active and adaptable skills.

Indeed, *health literacy is active*: As society changes, so do the necessary literacy skills needed to function. Citizens have to continually learn new information and un-learn outdated information in order to guide their health decisions.

*Health literacy is also dynamic*: Health literate individuals are involved in continuous exchange and dialogue with their environment. They are able to balance autonomy and dependency in their interactions with health professionals, patient organisations, and all services in the community (European Health Policy Forum, 2005).

## 3. Building health literacy is more than providing health information

Access to good, reliable information is the cornerstone of health literacy. Yet providing information, even good information, is often not enough. Somehow, we need to build in the right communications channels to make sure that health information translates into healthy behaviours.

For example, the internet and *e-health* are increasingly seen as a potential vehicle to citizen empowerment (eHealth declaration, 2003). Yet computer literacy is far from universal across Europe. It is particularly low amongst older people. For example, only 1% of persons over the age of 60 in Greece have access to a computer (Salifiou C., personal communication 2004).

Even the most well-thought out health education campaigns are sometimes not effective. For example, despite having amongst the most advanced sexual health education in schools, the United Kingdom has one of the highest rates of chlamydia and of unwanted teenage pregnancies in the EU.

Somehow, we need to determine how  
health information  
can translate into healthy behaviours.

‘Health information alone will not be useful to people who do not feel they have the power to act. Other complementary strategies are needed, such as community development and participatory health education...The health care system also needs to acknowledge the lack of power which many people feel, and to explore ways in which it can assist people in taking more control over their lives and their health.’  
(Health Canada, 2003)

## C. The prevalence and costs of poor health literacy

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### I. Prevalence

It is difficult to quantify the prevalence of poor health literacy. Few studies exist which have measured it and estimates differ in their definitions and methodologies (Institute of Medicine, 2003).

Existing data point to huge gaps in health literacy across the population. For example, a Canadian survey found that 22% of Canadians were unable to read a medicine label and correctly calculate the required amount of medicine to give to a child. Half of Canadians had difficulty reading materials required for everyday life (Human Resources Canada, 1997).

We need further research on ways to measure health literacy across populations. In Europe, empirical data on the prevalence of low health literacy is needed to quantify the scale of the problem and propose appropriate solutions across different groups of society.

### **How health literate are we?**

In 2005, the National Consumer Council in the United Kingdom ran a survey on health literacy among 2,000 adults (NCC, 2004; 2005). It found that one in five people had problems with the basic skills needed to understand simple information that could lead to better health.

The survey found that poorer sections of the community were less likely to seek information or help for health problems. For example, 45% of people in the highest social groups asked their GP questions, as compared to 35% of lower socioeconomic groups. 39% of those better-off would search the internet for information about their health, compared to 16% in lower socioeconomic groups.

Source: National Consumer Council, 2005

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## 2. Economic impact

Poor health literacy may have consequences not only for individuals or the health care system, but for society at large. An American study estimated that low health literacy costs the American economy up to **\$73 billion per year** (American Medical Association, 2003). This and other studies found that people with low health literacy:

- are more likely to use emergency services
- are more likely to be hospitalised
- are less likely to be compliant with medicines
- are less likely to use preventive services
- incur higher health care costs.

Europe is spending millions on the healthcare sector that may easily be prevented with improved health literacy. Investing in health literacy may improve population health and reduce health care costs.

## 3. Balancing equity and choice

Improvements in health literacy will help overcome health inequalities. Yet policies promoting more choice for citizens may run the risk of creating a two-tiered system in terms of access, where individuals with health literacy are able to exercise greater choice, whilst vulnerable groups, such as the elderly, disabled, less educated, or socially excluded, 'fall through the net'.

We cannot afford to disenfranchise the more vulnerable groups of society in our push towards more 'informed and engaged' patients. Policies advocating greater choice in health care should lessen health inequalities, not exacerbate them.



## D. Health literacy is a public health imperative

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### 1. Health literacy skills are needed in sickness and in health

The Ottawa charter for health promotion states that ‘health is created in the context of everyday life, where people live, love, work and play’ (WHO, 1986). It follows that we need health literacy skills in our capacity as citizens, consumers, and patients.

Thus health literacy skills include:

1. *Basic health competencies* and the application of health promoting, health protecting and disease preventing behaviours, as well as self-care.
2. *Patient competencies* to navigate the health system and act as an active partner to professionals.
3. *Consumer competencies* to make health decisions in the selection and use of goods and services and to act upon consumer rights if necessary.
4. *Citizen competencies*, through informed voting behaviours, knowledge of health rights, advocacy for health issues and membership of patient and health organizations.

### 2. Poor health literacy is a key component of health inequalities

Studies have shown that low functional literacy is linked to poorer health outcomes (Scholman, 2004; Brown *et al*, 2003). It follows that low *health* literacy may be a strong contributor to health inequalities – and that this relationship is reciprocal. Reducing the gap in health literacy may help reduce some of the inequalities which plague our European societies in terms of life expectancy, outcomes of care and mortality. As was recently advocated by the WHO, allowing these inequalities to persist in our wealthy societies is nothing short of social injustice (WHO 2004).

*‘Good health involves reducing levels of educational failure, reducing insecurity and unemployment and improving housing standards. Societies that enable all citizens to play a full and useful role in the social, economic and cultural life of their society will be healthier than those where people face insecurity, exclusion and deprivation.’*

(The Solid Facts, 2004)

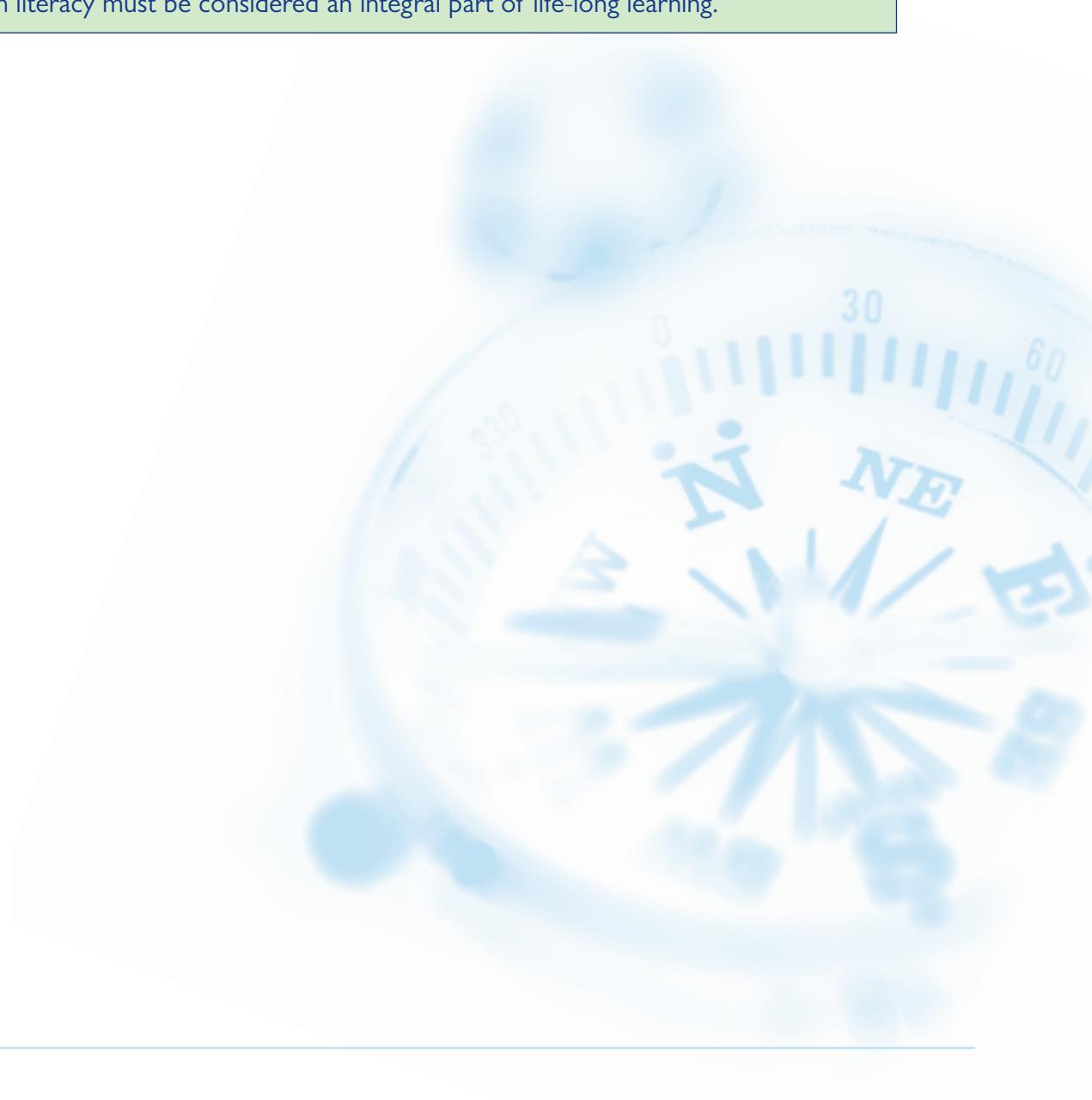
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### 3. Health literacy is a key component of life-long learning

Europeans are living longer and healthier lives than ever before (Healthy Ageing — Longitudinal Study Europe (HALE), 2004). However, opportunities for 'healthy ageing' do not apply equally across the population. Significant gaps in life expectancy and disability levels exist across populations. Much of this gap is due to the impact of social determinants of health which persist throughout life.

Many studies have shown that older age can be a barrier to health literacy (Baker et al, 2000; Henderson et al, 2004; Chew et al, 2004). Health literacy skills and needs may evolve over people's lives. The WHO Active Ageing Initiative advocates that building health literacy is key to promoting active ageing (WHO 2002).

Policy efforts aimed at improving health literacy must target people of all ages. Building health literacy must be considered an integral part of life-long learning.



## E. What works? Taking responsibility

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### I. Joint ownership: the need for European partnerships

Health is not just the product of professional activities. It is a resource for individuals and society, a co-produced good and a shared responsibility across many sectors and social areas. It follows that health literacy is a shared responsibility amongst all actors of society, with citizens at the core.

Putting health and health literacy at the heart of EU policy making is a shared responsibility. If we are to improve the health of Europeans, then policymakers, governments, citizens, public health agencies, employers, health professionals, social services, insurers, patient groups, NGOs, the media and many more need to collaborate to take common action. The role of the private and voluntary sector should not be overlooked.

Europe must continue to play a key role in fostering this collaboration. The **European Health Policy Forum**, for example, creates a platform for all those involved in European public health issues and may help achieve more active coordination across member states (European Health Policy Forum, 2005). European Platforms such as the **European Platform for Action on Diet, Physical Activity and Health** also provide opportunities for different member states to take action to address health issues and build health literacy within their local contexts.

Through effective partnerships, a core of excellence and expert knowledge surrounding health literacy may be created at a European level. Ideally, this core of knowledge could form the foundation for the establishment of a European Centre of Excellence on Health Literacy.

### 2. National leadership in building health literacy

Targeted national campaigns and programmes on health literacy may provide a powerful steer to localised campaigns and initiatives. Examples of such initiatives exist in:

- *Canada*: a national survey on health literacy was first conducted in 1994. Dedicated actions and websites committed to building health literacy exist at the national and provincial level (Health Canada, 2003);
  - *The United States*: the Institute of Medicine issued a landmark study on Health Literacy entitled 'Health Literacy: The End of Confusion' in 2003 and has since led the only economic evaluation of health literacy (Institute of Medicine, 2003);
-



A poster from the Irish Health Literacy campaign

- *The United Kingdom:* In a collaboration between the Departments of Education and Health, the government launched *Skills for Health* to look at how health literacy could be developed in specific settings. In 2006, it established a National Health Literacy Collaborative, linking community-level projects with national policy.
- *Ireland:* A national health literacy survey conducted in 1997 has led to a national programme on health literacy. It provides Literacy Awareness Training for health practitioners and a comprehensive adult literacy-friendly health pack designed as a learning tool for people with literacy difficulties. All materials are available electronically ([www.nala.ie/projects/](http://www.nala.ie/projects/)).

### 3. Bridging from grassroots initiatives to national policies

There are several excellent initiatives to build health literacy across Europe. However, too often, they tend to remain at a grassroots level. Lessons learnt are not transposed to other contexts or communities, nor do they feed into policies being developed. The gap between policy and practice needs to be bridged in both directions.

Without central support, grassroots efforts may not achieve to ensure quality and evaluation. Micro-level interventions need to be integrated with policy building and the provision of supportive environments.

#### **Building from setting-dependent initiatives through regional policy: health literacy in Germany**

In Germany, various prevention projects are currently being run targeting socially disadvantaged groups. These projects are of mixed quality, and lack an integrated quality management or evaluation system. An initiative was designed to link these setting-based projects to the political/policy arena. The aim was to ensure that the projects could be sustainable, whilst respecting their authenticity and local specificity. The programme provides a network for exchange between local projects as well as facilitators to help with quality improvement and evaluation.

([www.gesundheitliche-chancengleichheit.de](http://www.gesundheitliche-chancengleichheit.de))

## 4. It's not just about building individuals' health literacy

For our societies to become health literate, all actors involved need to increase their health literacy:

- *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 engage in care decisions,
- *Professionals* need to tailor their communication to meet the needs of their patients and see it as their responsibility to foster their 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.

To be a health literate society, we need a health literate public, health literate health professionals and health literate politicians and policy-makers.

## 5. Building professional health literacy

Governments, medical schools and continuing education programmes may help health professionals develop their own health literacy. A key component to this is good communication and listening skills. Education efforts must extend to nurses, community health workers and all relevant health and social care professionals.

### **The Migrant-Friendly Hospitals Initiative:**

*Professional training in cultural competence*

This initiative is a collaboration between a wide range of health experts, NGOs and hospitals aiming to put migrant-friendly and culturally-competent health care and health promotion higher up on the EU policy agenda. It supports interested hospitals by providing them with practical knowledge and tools aimed at improving their migrant-friendliness. Such tools include improved interpreter services, migrant-friendly information and training (eg. for mother-child care), and staff training in cultural competence. This initiative recognises the importance of building the health literacy of both professionals and patients in order to remove barriers to good care for migrant users (LBISHM, 2005)



### Migrant health: a collision of cultures

Culture shapes perceptions of illness and health, which in turn influence people's experience and attitudes towards health and the health system (Institute of Medicine, 2003). This is true of individuals both receiving and delivering health services.

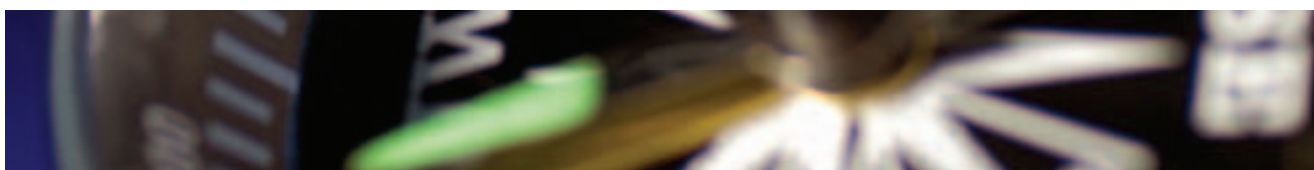
Migrant health is a perfect illustration of the need for health literacy to be interactive and two-sided. With health literacy as an enabler both for the patient and the professional, a true dialogue may be established.

#### Migrant patient

#### Local doctor

Own cultural approach and values regarding health	<ul style="list-style-type: none"> <li>• Find a common ground for approaching the health situation</li> <li>• Dialogue and discussion encouraged by both</li> <li>• Listening</li> <li>• Reciprocal learning</li> <li>• Climate of trust and partnership</li> <li>• Use of interpreter or translator services, if available</li> <li>• Engagement of relatives into discussions about care options</li> </ul>	Duty of care defined by training and medical culture.
Possible mistrust of local approaches to care		Possible ignorance or preconceived notions of patient's cultural attitudes to care
Language barriers		May not speak patient's language
Family context, influence of relatives		May not consider family context or influence
Financial barriers, lack of insurance		Lack of time, limited resources, limited flexibility in adapting standard practice

———— Patient health literacy —————><———— Professional health literacy —————



## 6. Placing health messages within their appropriate social context

Individuals facing health decisions belong to families, relationships, communities and social groups. This context – familial, social – should not be forgotten in targeted efforts to vulnerable groups.

Too often, public health campaigns make the mistake of **‘de-contextualising’** people from their social contexts.

For example:

- Interventions to improve nutrition should not only be taught in schools. The entire family needs to be engaged.
- Maternity services for migrant women too often forget to involve their partners, mothers and relatives. Yet their engagement is essential in cultures in which childbirth and child-rearing are a community responsibility.

Single-issue health campaigns are unlikely to be effective if the social context for health is not targeted at the same time. Health messages and solutions must be placed within settings relevant to their target audiences and encompass both a social and health dimension.

## 7. Finding the ‘hook’ to foster personal responsibility

Messages about healthy behaviours often fail to reach those who need to hear them most. Public health messages that are not tailored to the individual and the individual’s circumstances are likely to be ignored.

Public health messages will only reach target audiences if they find the right ‘hook’ to make messages relevant to those hearing them.

What is needed is to find the hook to engage individuals: place messages within contexts of relevance to them. This cannot be achieved by a one-size-fits-all health promotion campaign. Somehow the message that needs to get across is ‘health is an investment for your future. Health will enable you to stay active longer, to be a better parent, to be happier.’

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## Finding the social hook: the case of obesity

The case of obesity is illustrative of many of the challenges of building health literacy.

There is a deluge of information. Yet somehow messages are failing to reach those who are most at risk of obesity: the poor, the less educated and the socially excluded.

Some important lessons learnt are:

- Personal circumstances enabling or preventing individuals to act upon specific information have to be considered.
- If people are blamed for things they feel they have no control over, then they give up.
- Empowering individuals means giving them the confidence to become and stay healthy, not merely to correct 'wrong' behaviours.

Information needs to be sensitive to culture, attitudes, competing stresses and priorities of the individuals they are targeting. Input from target audiences is needed to make sure the most effective and meaningful language and communication is used.

## 8. Adopting a gender perspective

Men and women may have very different attitudes towards health and health-seeking behaviours. Women are more likely to take responsibility for the health of their children and relatives, thus they are a key conduit to health promotion within communities.

**Yet paradoxically, this central role within the family may make women less 'health literate' when it comes to their own needs.** This has clearly been documented in the case of heart disease, and huge health promotion efforts have tried to raise awareness amongst women about their cardiac health risks.

The health of men should also not be forgotten. There is growing research into the specific attitudes and approaches with which men tackle health and health decisions. Men are often forgotten in health promotion messages. Rates of obesity in men, for example, exceed those in women, yet most diet and well-being messages are targeted at female audiences.

Further research, more targeted messages and more gender-sensitive approaches to build health literacy and 'push the right buttons' to engage men and women of all ages in their health are urgently needed.

## F. Conclusions and Recommendations

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### The right to health literacy

- **Health Literacy is a right of citizenship:**

Health literacy is part of the fundamental skills needed to function in modern society. Just as there is a universal right of access to healthcare, the universal right of access to health literacy must be recognised.

### Political engagement and accountability

- **Create a voice for health literacy in the political process**

Health literacy must be raised to the political agenda and have designated advocates within the political process. The voluntary sector also has a clear role to play in advancing policies on health literacy.

- **Politicians, professionals and the public all must take responsibility for health literacy**

To achieve our population health goals for Europe, the public, professionals and politicians all need to build their health literacy. Health literacy is a joint responsibility.

### Investment of resources

- **Governments must commit to long-term investment in health**

Building health literacy is a long-term strategy that requires investment. Low health literacy incurs significant costs to society.

- **Build partnerships to promote health literacy**

Health is too important a facet of society to be the sole responsibility of the health care sector. Governments should provide supportive environments that foster the growth of health literacy. Multisectoral approaches are needed, as are partnerships between the private, public and voluntary sector.



## Building supportive environments

- **Adopt a multilevel approach in health literacy building**

To reach target populations, initiatives to build health literacy must be setting-dependent. At the same time, grassroots efforts need supportive environments to ensure that they are sustainable. More collaboration between grassroots initiatives and central policies is needed.

- **Invest in new types of professionals**

To guide individuals towards their health goals, new professionals are needed in the community and in all clinical settings who may act as advocates, counselors and guides.

## Capacity building in the community

- **Health literacy should be put on the school curriculum**

Strategies to build health literacy must be viewed as part of life-long learning. Health literacy should be integrated into the school curriculum from a young age.

- **Enabling health literacy in health settings**

Health care systems need to adapt to empower individuals and promote health literacy. Professionals must see it as part of their duty of care to develop the health literacy skills of their patients. Training of all health professionals is essential.

## Health literacy as a public health imperative

- **Building health literacy to reduce health inequalities**

Efforts to promote health literacy must recognise the diversity of individuals and communities in their approaches to health. The role of family, social context, culture and education need to be factored into the development of all health literacy messages and proposals.

- **Develop more simple and practical information**

Providing meaningful and reliable information is a necessary starting point to building health literacy. Health information materials should be sensitive to differences in cultures, gender, and individuals in their content and format.

## A priority for European research

- **Create a European Centre of Excellence on Health Literacy**

- **Develop a research and network agenda on health literacy in the European Union**

The European Union has a critical role to play in creating opportunities for further research on health literacy. Surveys of health literacy (similar to the PISA study) should be created. Health Literacy should be put on the agenda of the EU Health Policy Forum. Dedicated research funds should be made available.

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