

SECRETARIAT GENERAL

Directorate General of Democracy



**Results
of the survey on citizens' consultation
on the right to the protection of health**

Summary Report

by
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Content

Executive summary	5
1 Introduction.....	7
2 Key concepts	11
3 Methods.....	17
4 Results.....	19
4.1 Enablers for health literacy and citizens' consultation.....	19
4.2 Health Literacy.....	22
4.3 Citizens' consultation	31
4.4 Ten notable practices from member states regarding citizens' consultation.....	36
5 Discussion and recommendations	41
5.1 Reflection on Health literacy findings.....	41
5.2 Reflection on citizens' consultation findings.....	42
5.3 General reflections on the survey results.....	43
5.4 How could citizens' consultation be taken forward in member states of the Council of Europe	43
6 References	45
Appendix 1.....	47

Executive summary

The role of citizens is of increased importance in the process of creating health-centered, people-centered systems and societies. To respond to the demands for partnerships and co-production of health between citizens and authorities, new perspectives are needed. Authorities and public officials will need to support and facilitate people to navigate health for themselves, their families and the wider community. In addition, authorities are called to collaborate with citizens to raise awareness and advance competencies and pave the way for change concerning health-related matters through consultation and engagement. Various stakeholders and organisations have highlighted the relevance for citizens' consultation in modern democratic societies. The Council of Europe sees citizens' consultation as a vital mechanism to strengthen citizens' democratic rights, to make use of modern communication technology and to improve the quality of health care and health policy processes.

In addition, an investment in health literacy is crucial, as health literate populations and health literate organisations are essential cornerstones in the process of creating healthy societies. Health literacy is closely linked to literacy and entails the knowledge, competencies and motivation to access, understand, appraise and apply information, to form judgments and take decisions in terms of healthcare, disease prevention and health promotion, to maintain and promote quality of life throughout the life course. To support member states in strengthening these aspects in an integrated manner, the Council of Europe initiated a project entitled "Model of a citizens' consultation platform on the right to the protection of health" in 2012-2013. The project is being carried out under the supervision of the European Committee for Social Cohesion (CDCS), and it aims at reviewing the actions member states have taken with regard to consultation with their citizens on health issues. As an essential condition for social cohesion, the project aims to support member states in improving the consultation on health issues with their citizens. This should be achieved by reviewing existing good practices on the promotion of health education and health literacy as well as on consultation and communication mechanisms, and to derive a Citizens' Consultation Platform as a 'good practice' template, which can be used by policy makers, planners, medical professionals and other stakeholders across the member states.

The Survey took place from March to November 2012. A project team consisting of staff from the Council of Europe and the Department of International Health of Maastricht University, which is hosting the Health Literacy Europe Network, developed the survey questionnaire. The questionnaire included a total set of 23 quantitative and qualitative items on the following issues: legislation, policy and practice, equality and non-discrimination, children and young people, women, citizen's consultation, examples of good practice and 'the way forward'. The survey methodology was chosen to facilitate a 'quick scan' of existing infrastructures and processes for citizens' consultation and health literacy. The data analysis referred to the advancement of health literate populations and organisations; and the development of

Results of the survey on citizens' consultation on the right to the protection of health

citizens' consultations in member states. Ten notable practices were identified and explained in detail according to the OECD model of citizen engagement.

The main conclusion of the report is that member states are prioritizing health of citizens through legal mechanisms, general health education, capacity building, and health service provision and a shift can be traced towards a more people-centered approach. The change process reveals some countries to be frontrunners with numerous examples of initiatives including health literacy strategies and engaging partnerships. Yet, other countries are in a time of transition, where initiatives can be characterized as top-down, with a focus *for* people, rather than *with* people. The notable practices on health literacy included examples of country activities concerning building the conceptual foundations, as well as the enhancement of critical skills and civic orientation which are fundamental to the active partnerships wished for in the implementation of strategies regarding citizens' consultations. In addition, it was possible to identify examples of the ten attributes of health literate systems and organisations, which indicate that health and health literacy is becoming a strategic value in some countries. The ten notable practices on citizens' consultations in particular emphasise the need to be more proactive in the facilitation of collaboration and establishment of partnerships. Though the progress is slow, the trends shown in the survey point towards a steady growth towards a more inclusive European society with regard to protecting people's health.

1 Introduction

The impact of health literate and engaged citizens in health: shaping healthy societies in the 21st century

Whereas many health systems have been designed to avoid illness and treat diseases a new focus is increasingly being adopted to shape healthy societies in the 21st century. The focus implies shifts away from the practitioner–patient consultation to the skills that individuals employ to evaluate health information within the context of their lives and throughout their life course. The role of citizens is of increased importance in the process to create health-centered, people-centered systems and societies. To respond to the demands for partnerships and co-production of health between citizens and authorities, new perspectives are needed. Authorities and public officials will need to support and facilitate people to navigate health for themselves, their families and the wider community. In addition authorities are called to collaborate with citizens to raise awareness and advance competencies and pave the way for change concerning health-related matters through consultation and engagement. An investment in health literacy is crucial, as health literate populations and health literate organisations are essential cornerstones in the processes of creating healthy societies.

The protection of health and the public consultation processes are important values for the Council of Europe and its member states. The aim of the Council of Europe is to protect and promote human rights, pluralist democracy and the rule of law. The right to the protection of health is enshrined in the Council of Europe's European Social Charter (1961) and Revised European Social Charter (1996), clearly defining the responsibilities and obligations of the States Parties in this context. According to Article 11 of the Charter, member states are obliged to take appropriate measures to:

- Remove the causes of ill-health;
- Provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
- Prevent epidemic, endemic and other diseases, as well as accidents (European Social Charter, 1996).

Furthermore, Article 28 of the Oviedo Convention states that member states are obliged to regularly engage in public discussions with their citizens about the medical, social, economic, ethical and legal implications of developments in biology and medicine (Council of Europe, 1997). Previous activities have contributed substantially to strengthening the understanding and role of citizens' consultation in the health sector. The Council's recommendation on "The Development of Structures for Citizen and Patient Participation in the Decision-making Process" recognizes that empowering citizens revitalizes representative democracy, enhances social cohesion, leads to the better functioning of the health care system, and established a better balance of interest and a partnership between the various player in the

Results of the survey on citizens' consultation on the right to the protection of health

system (Council of Europe, 2000). Subsequent Council of Europe recommendations and activities have aimed at enhancing these consultation processes. In the late 1990's the Council of Europe set up a study group on patient/citizen participation in health care and commissioned an appraisal of available structures for patient/citizen participation in the decision-making processes in the member states. This was followed by various recommendations and initiatives that highlighted the role of citizen participation as an important element for any health matters¹.

To support member states in strengthening these aspects in an integrated manner and to update the appraisal from the late 1990's, the Council of Europe initiated a project entitled "Model of a citizens' consultation platform on the right to the protection of health" 2012-2013. The project is being carried out under the supervision of the European Committee for Social Cohesion (CDCS), and it aims at reviewing the actions member states have taken with regard to consultation with their citizens on health issues. As an essential condition for social cohesion, the project aims to support member states in improving the consultation on health issues with their citizens. This should be achieved by reviewing existing good practices on the promotion of health education and health literacy as well as on consultation and communication mechanisms, and to derive a Citizens' Consultation Platform as a 'good practice' template, which can be used by policy makers, planners, medical professionals and other stakeholders across the member states.

In order to effectively execute the project, the Council of Europe has decided to engage with Health Literacy Europe, a network of European organisations and individuals, with the objective to improve health literacy in Europe and to empower European citizens to play a role in today's health systems. Health Literacy Europe is hosted by the Department of International Health at Maastricht University in the Netherlands. To meet the objectives, a survey was developed and circulated among the Council of Europe member states aiming to provide insights into:

- Member states' current methods to consult with citizens on health issues and the protection of health
- Existing good practices of citizen's participation in health-related decision making
- Member states' approaches to citizen empowerment regarding the protection of health.

¹ For examples on how citizens' consultation has been embraced in the work of the Council of Europe, please consider the following Committee of Ministers recommendations :

CM/Rec (1997)17- Recommendation on the development and implementation of quality improvement systems in Health care

CM/Rec (2000)5 - Recommendation on the development of structures for citizen and patient participation in the decision-making process affecting health care

CM/Rec (2006)7- Recommendation on management of patient safety and prevention of adverse events in health care

CM/Rec (2010)6 – Recommendation on good governance in health care systems

CM/Rec (2012)8 - Recommendation on implementation of good governance systems in health care systems

Results of the survey on citizens' consultation on the right to the protection of health

This report provides an overview of the results from the survey on citizen's consultation on the right to protection of health. Following the introductory chapter, chapter 2 provides an overview of the key concepts "health literacy" and "citizens' consultation" that are of relevance for this assessment. Chapter 3 describes the methods used, including a description of the development, application and analysis of the survey that was distributed to all 47 Council of Europe member states. This is followed by a presentation of results in chapter 4, including a summary of the reported good practices. The report closes with a critical reflection on the findings and a proposal for suggested ways forward in terms of recommendations for improving health literacy and consultation mechanisms in the member states in chapter 5.

Results of the survey on citizens' consultation on the right to the protection of health

2 Key concepts

This chapter clarifies the two key concepts of “health literacy” and “citizens’ consultation” applied in the context of the Council of Europe project and presents the two related analytical frameworks applied in the subsequent survey analysis.

2.1 Citizens’ consultation

Citizens’ consultation has been recognized as an important mechanism in democratic societies. The Council of Europe has stated that it is a fundamental right of citizens in free and democratic societies to determine the goals and targets of the health sector (Council of Europe, 2000a). Over the past decade, the concept of citizen involvement in public decision-making processes has been widely discussed and a plethora of terminologies have evolved. Terms such as civil participation, citizen engagement, public dialogue, participatory democracy and public involvement are often being used interchangeably, depending on the particular context. As a working definition, this report applied the term ‘citizens’ consultation’, which has been defined by the Council of Europe’s Conference of International Non-Governmental Organisations (INGOs) as: “a process which facilitates interaction and enhances citizens’ empowerment and participation in the democratic process at local, regional and national levels” (2009).

Various stakeholders and organisations have highlighted the relevance for citizens’ consultation in modern democratic societies. The Council of Europe sees citizens’ consultation as a vital mechanism to strengthen citizens’ democratic rights, to make use of modern communication technology and to improve the quality of health care and health policy processes (Council of Europe, 2000a). In a similar vein, OECD (2001) issued a policy brief in which citizens’ consultation is described as a tool to add value to policy processes, as it:

- provides additional ideas, information and resources for making decisions
- meets the challenges of the emerging information society
- responds to citizens’ expectations
- increases transparency and accountability
- builds public trust (OECD, 2001).

Generally, citizens’ consultation can be applied in various different contexts and at various levels of the health system. This report focuses on two main areas: citizens’ consultation in health care and citizens’ consultation in health policy matters. This is reflected by two different terminologies: ‘patient consultation’ and ‘citizens’ consultation’. The literature suggests multiple frameworks for consultation in these two areas. Notably, frameworks from both fields have in common that they provide different levels of engagement for citizens’ consultation. For this report, it was decided to adopt an existing framework from Patterson Kirk Wallace, which originated in Canada but was disseminated and applied globally,

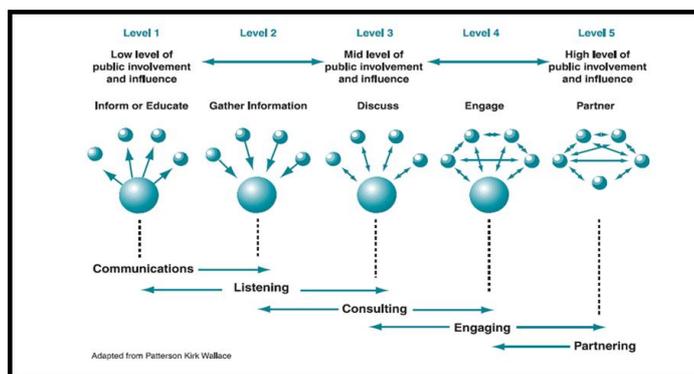
Results of the survey on citizens' consultation on the right to the protection of health

including some European countries such as Ireland² or the UK³ (Figure 1). The framework focuses on different levels of engagement for citizens' consultation. The framework differentiates between five levels although the boundaries between these levels are fluent and many hybrid forms can exist. The five levels include:

- 1 **Informing or Educating:** One-way information exchange; The public needs to know about the results of a process. A decision has already been taken.
- 2 **Listening:** One-way information exchange; The purpose is to gather information. Decisions are still being shaped; no firm commitment to the views collected.
- 3 **Consulting:** Two-way information exchange; Individuals and groups have an interest in the issue and will be affected by the outcome; Input may shape policy directions/program delivery.
- 4 **Engaging:** Round table discussion; Citizens need to discuss complex, value-laden issues; Capacity for citizens to shape policies and decisions that affect them
- 5 **Partnering:** Citizens in the 'drivers seat'; citizens to manage the process and government acts as an enabler.

Although this framework relates mainly to levels of engagement for citizens' consultation in health policy processes, it can also be used in the context of health care processes, as the different dimensions also apply there. These five dimensions were used as analytical point of departure for the identification of good practices from the member states (see also chapter 4).

Figure 1: Analytical framework regarding 5 levels of citizens' consultations



2.2 Health literacy

Health literacy is closely linked to literacy and entails the knowledge, competencies and motivation to access, understand, appraise and apply information, to form judgments and take decisions in terms of

² See: *Health and Social Care Regulatory Forum. (2009). Health and Social Care Regulation in Ireland. Available at: <http://www.rpii.ie/RPII/files/62/62f874c3-65e6-4b93-b923-695a3c8ba9bf.pdf>*

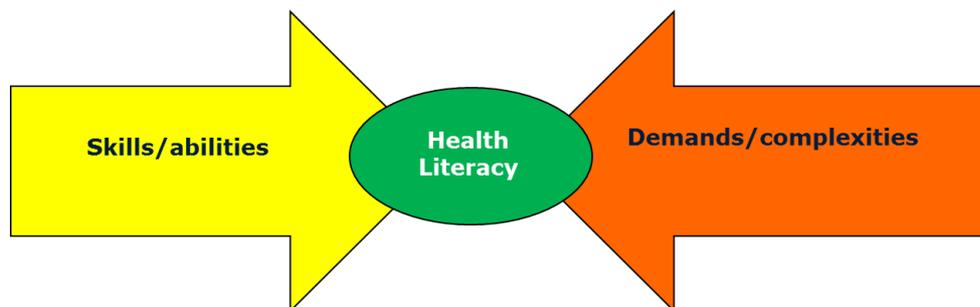
³ See: *Health Care Quality Improvement Partnership. (2009). Patient and Public Engagement (PPE). Available at: <http://www.hqip.org.uk/assets/PPE/HQIP-PPE-Guidance.pdf>*

Results of the survey on citizens' consultation on the right to the protection of health

healthcare, disease prevention and health promotion, to maintain and promote quality of life throughout the life course (Sorensen et al., 2012). Health literacy is influenced by personal determinants, the situational context as well as the broader societal and environmental determinants. Health literacy in turn influences health service use and health costs; health behavior and health outcomes; community and societal participation associated with empowerment; and equity in relation to sustainability from an individual and societal perspective (Sorensen et al., 2012). Kickbusch et al. (2006) summarise health literacy as “the ability to make sound health decision(s) in the context of everyday life at home, in the community, at the workplace, the healthcare 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”.

An individual’s skills are not applied in vacuum; society, community, and the healthcare, education and social systems will mediate the impact of skills on health (Rowlands et al., 2012). Parker and Ratzan illustrate in figure 2 how there are two sides to the equation that needs to be considered; the skills that citizens need to become health literate, and the health literacy of society and its systems (2010). The best results for the people and the society are when the skills of the populations match the demands and complexity of the systems and allow an efficient communication and use of services and rights.

Figure 2: Framework showing the dual nature of communication in health literacy



Parker and Ratzan: **Framework showing dual nature of communication in health literacy**. Health Literacy: A Second Decade of Distinction. Journal of Health Communication, 15:2:2010

2.3 Analytical framework for health literacy

The analytical framework (see figure 3) for the analysis of data from the survey on health literacy is grounded in the work of Parker & Ratzan (2010); Freedman et al. (2009); and Brach et al. (2012). In practice, the framework of Parker and Ratzan is adapted to include three attributes for developing the population’s health literacy as outlined by Freedman et al. on the left side of the framework. On the right

Results of the survey on citizens' consultation on the right to the protection of health

side, the ten attributes of a health literate organisation outlined by Brach et al. is added to show how a health literate system can be recognized. The attributes are described in details in the following.

2.3.1 Public health literate populations

Freedman et al. (2009) highlight three areas of importance in terms of developing public health literacy:

1. Conceptual foundations, which include the basic knowledge and information needed to understand and take action on public health concerns. People or groups with high level of public health literacy will focus on prevention rather than treatment and would take into account the multiple factors affecting health, including the role of community settings and structures, as well as individual behaviours and lifestyles. An individual or group demonstrating public health literacy at a conceptual level is able to define and discuss:

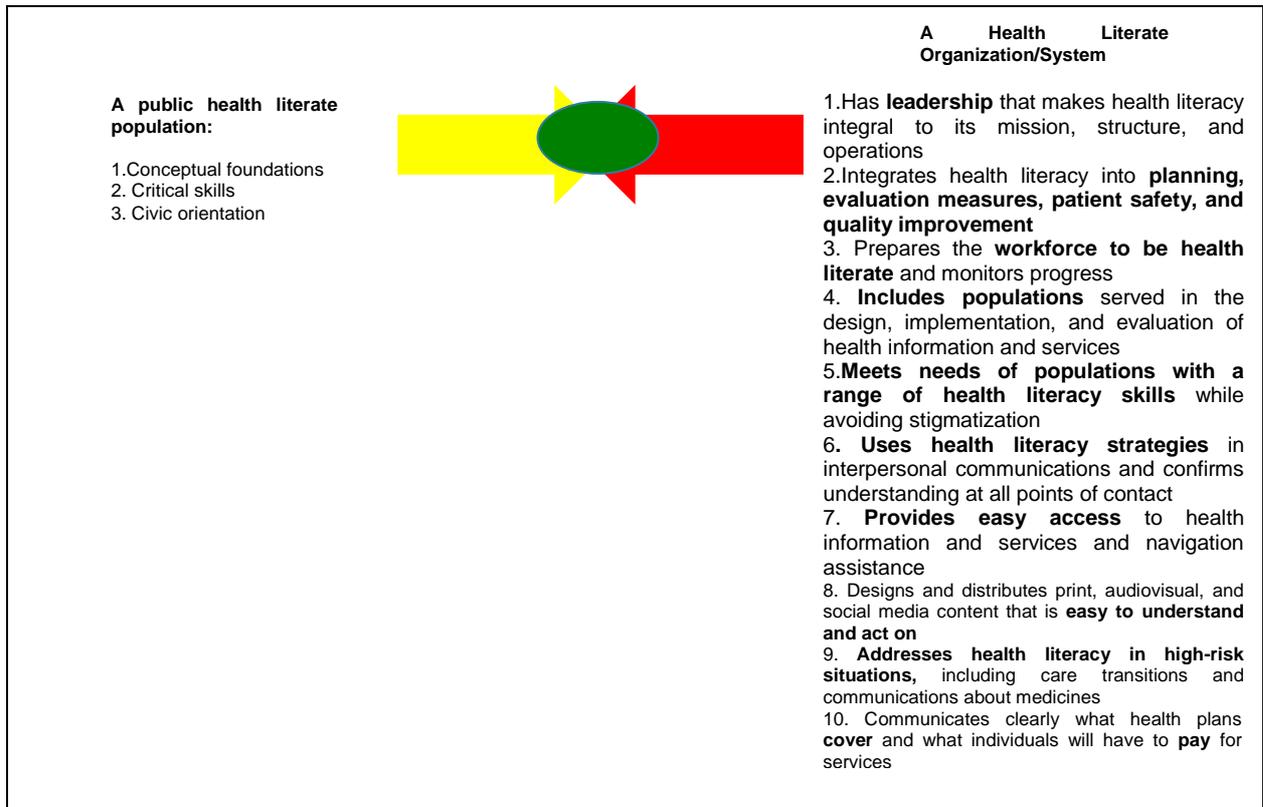
- core public health concepts such as primary prevention, health promotion, and population health
- public health constructs such as prevalence, risk factors, probability, and ORs, and the relationship of each of these to morbidity and mortality
- ecologic perspectives and the multiple pathways through which disease is transmitted and health is promoted.

2. Critical skills, which relates to skills necessary to obtain, process, evaluate, and act upon information needed to make public health decisions that benefit the community. Critical skills focus on promoting the health of the community rather than the health of the individual. In doing so, citizens are able to understand public health aspects of personal and community concerns. In addition, people or groups with high levels of public health literacy have the skills to communicate personal health conditions in terms of problems affecting the broader community and to shift conversations and actions about public health concerns from individual level to community level. These skills tend to refocus discourse about public health problems as well as corresponding actions to reveal the biographic, cultural, spatial, temporal, and institutional constraints on understandings of public health. e.g. an individual or group demonstrating public health literacy on this dimension is able to:

- obtain, evaluate, and utilize public health information from a variety of sources (e.g. health practitioners, media, social networks)
- identify public health aspects of personal and community concerns (e.g. urban planning, agricultural practices, violence)
- communicate information about health conditions and actions (e.g. smoking, obesity, handwashing) not only as a personal concern but also as a problem affecting the larger community
- assess who is naming and framing public health problems and solutions and describe the ways in which such framing is biographically, culturally, spatially, temporally, and institutionally bounded.

Results of the survey on citizens' consultation on the right to the protection of health

Figure 3: Analytical framework including three attributes for health literate populations and ten attributes for health literate systems



3. Civic orientation ensures that “the public” remains at the centre of public health literacy and includes the skills and resources necessary to address health concerns through civic engagement. Civic engagement calls for awareness of the ways that public goods, resources, burdens, and benefits are distributed; it is the first step toward civic action to advocate on behalf of the public’s health. An individual or group demonstrating public health literacy from a civic perspective is able to:

- articulate that the burdens and benefits of society are not fairly distributed
- evaluate who benefits from and who is harmed by public health efforts or lack thereof
- communicate that current public health problems are not inevitable and can be changed through civic action
- address public health problems through civic action, leadership, and dialogue.

2.3.2 Health literate organisations/systems

Brach et al. (2012) identified 10 areas of importance for the creation of health literate organisations. They are for the purpose of the study adapted to account for health literate societal systems as well (e.g. healthcare, social and educational systems). The attributes are described in details in table 1.

Results of the survey on citizens' consultation on the right to the protection of health

Table 1: 10 attributes of health literate organisations/systems by Brach et al. 2012

A Health Literate Organization	Examples
1. Has leadership that makes health literacy integral to its mission, structure, and operations	Develops and/ implements policies and standards Sets goals for health literacy improvement, establishes accountability and provides incentives Allocates fiscal and human resources Redesigns systems and physical space
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement	Conducts health literacy organizational assessments Assesses the impact of policies and programs on individuals with limited health literacy Factors health literacy into all patient safety plans
3. Prepares the workforce to be health literate and monitors progress	Hires diverse staff with expertise in health literacy Sets goals for training of staff at all levels
4. Includes populations served in the design, implementation, and evaluation of health information and services	Includes individuals who are adult learners or have limited health literacy Obtains feedback on health information and services from individuals who use them
5. Meets needs of populations with a range of health literacy skills while avoiding stigmatization	Adopts health literacy universal precautions, such as offering everyone help with health literacy tasks Allocates resources proportionate to the concentration of individuals with limited health literacy
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact	Confirms understanding (e.g., using the Teach-Back, Show-Me, or Chunk-and-Check methods) Secures language assistance for speakers of languages other than English Limits to two to three messages at a time Uses easily understood symbols in way-finding signage
7. Provides easy access to health information and services and navigation assistance	Makes electronic patient portals user-centered and provides training on how to use them Facilitates scheduling appointments with other services
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on	Involves diverse audiences, including those with limited health literacy, in development and rigorous user testing Uses a quality translation process to produce materials in languages other than English
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines	Prioritizes high-risk situations (e.g., informed consent for surgery and other invasive procedures). Emphasizes high-risk topics (e.g., conditions that require extensive self-management)
10. Communicates clearly what health plans cover and what individuals will have to pay for services	Provides easy-to-understand descriptions of health insurance policies. Communicates the out-of-pocket costs for health care services before they are delivered

3 Methods

The survey took place from March to November 2012. A project team consisting of staff from Council of Europe Secretariat and the Department of International Health at Maastricht University, which is hosting the Health Literacy Europe Network, developed the survey questionnaire. The questionnaire included a total set of 23 quantitative and qualitative items on the following issues: legislation, policy and practice, equality and non-discrimination, children and young people, women, citizen's consultation, examples of good practice and 'the way forward'. The survey methodology was chosen to facilitate a 'quick scan' of existing infrastructures and processes for citizens' consultation and health literacy.

The data collection process (i.e. the application of the survey in the member states) was led by the Council of Europe Secretariat and followed a key-expert approach. National experts from the Ministries of Health for each respective member state were identified and contacted by the Council of Europe Secretariat via the European Committee for Social Cohesion (CDCS) with the request to participate. Out of 47 contacted Member States, a total number of 22 countries (21 member states of the Council of Europe + Israel in its capacity as Presidency of the South East European Health Network, a cooperation partner to this project) replied to the survey (44%). Among the responding countries, eight also involved NGOs in the process.

The survey replies gathered by Council of Europe Secretariat were shared with the research team from Maastricht University for subsequent analysis. The quantitative items were analyzed using basic descriptive statistics to identify common patterns and conflicting views on certain issues across countries. For the qualitative sections of the survey, the responses from the 22 completed surveys were compiled per question and systematically reviewed in terms of the analytical frameworks related to health literacy and citizen's consultations. The analysis concerning health literacy was carried out by examining the data for relevance in terms of the three individual aspects of public health literacy: conceptual foundations, critical skills, and civic orientation; and for data relevant to the ten aspects of health literate organisations/systems. The analysis related to citizens' consultations referred to the assessment of the findings related to five levels of citizen engagement. The analysis allowed for the identification of recurrent themes and patterns across the responses, which could provide input for the development of recommendations and good practices. The preliminary results from this analysis were presented at a Council of Europe Workshop on 8-9 November 2012 in Strasbourg. The workshop helped to identify additional issues and to serve as an expert-validation of the findings.

4 Results

4.1 Enablers for health literacy and citizens' consultation

Citizen empowerment and consultation processes need to build on a strong legal foundation that ensures patients' and citizens' rights in the health care processes (Council of Europe, 2000a). In turn, citizen participation can be seen as a tool for the protection and implementation of these rights and policies in daily practice. The survey inquired issues that can be regarded as prerequisites for health literacy and citizens' consultation, including:

- access to health care and freedom of choice
- legal frameworks and policies relevant to citizens' consultation and health literacy.

4.1.1 Access to health care and freedom of choice

Ensuring equity and equal access to health care is a key priority for the Council of Europe and a central value for many European health systems. The aspects of equity and non-discrimination were explored by asking the member states if all citizens in their everyday life have equal access to health care services without discrimination (e.g. on the ground of age, sex, disability, sexual orientation, belonging to a minority groups, homelessness, prisoners, mental illness etc.). Furthermore, the survey explored to what extent information about quality, safety and performance of healthcare services was publicly available and accessible to all stakeholders, including elderly people and people with disabilities.

Concerning access to healthcare services in everyday life without discrimination, many responses indicated that this aspect was grounded in national constitutions and laws. One country mentioned the report to the Council of Europe relating to the implementation of the European Social Charter. Although countries in general indicated to do well, some countries highlighted that despite the fact that access is provided for by law, it may not always be the case in reality. Box 1 summarizes the answers.

In terms of the item that was concerned with citizens' free choice about their health care providers, all survey respondents 'agreed' or 'strongly agreed' to the statement that citizens were in general free in their choice of health care providers. Many experts referred to health care acts and additional legislation that created legal security for the citizens. The statements sketched the picture that freedom of choice of the health care provider was an important value of the member states' health system and a fundamental right of the patient. To what extent this was actually executed in practice was not appraised by the survey.

Box 1: Selected examples for ensuring equal access to healthcare services without discrimination

- **Armenia:** Equal access to healthcare services without discrimination is ensured through the Constitution of the Republic of Armenia and other legal acts regarding health.
- **Austria:** Almost 99% of the population is covered by the social insurance system. There is an electronic e-card system, which allows an overall access to health care facilities.
- **Azerbaijan:** The Constitution and the Law of the Republic of Azerbaijan on the "Protection of population health" state that all citizens have equal rights to access to healthcare services without any discrimination.
- **Bulgaria:** All citizens in their everyday life have equal access to health care services as regulated by the Health Act. Some target groups have more difficult access because of their location or lack of health contributions.
- **Croatia:** Direct and indirect discrimination on any grounds, including health status, are prohibited by the Anti-Discrimination Act. In December 2004, the Act on the Protection of Patients' Rights entered into force. Therefore, theoretically there is access to healthcare services in everyday life, but accessibility of healthcare in practice depends on the location in the country, the level of management and organisation of the specific institution, and financial efficiency.
- **Czech Republic:** Healthcare is provided without any discrimination. Health services are based on the principle of global access, equality and solidarity. The rights and obligations of patients and providers of health services are listed in the Health Services Act.
- **Finland:** Equal access to health care services for all is one of the main values in the Finnish health policy. The objective of the Finnish Health Care Act is, among others, to ensure universal access to services required and to improve quality and patient safety.
- **Lithuania:** The Constitution of the Republic of Lithuania provides for the principle of equal treatment (including equal access to health care services) for all persons irrespective of religion or belief, disability, age or sexual orientation etc.
- **Portugal:** The Portuguese Constitution states that all citizens, regardless of their age, sex, sexual orientation or social and economic status, have free access to health care services.
- **Romania:** All citizens have equal access to the health care system according to the law. Sometimes, access problems are related to culture or education (people do not know or do not want to ask for medical services). The health system organisation comprises mechanisms for insuring appropriate access (e.g. for the most important public health issues, health programmes are developed. All people have the right to access the programmes, even if they are not insured or do not have identity papers (e.g. homeless people). For example, all people having HIV receive free ARV treatment.
- **Serbia:** Law on health care, Article 26: Right to accessibility of health care. Patients

Results of the survey on citizens' consultation on the right to the protection of health

have the right to equal access to health services without discrimination on the ground of financial resources, residence, type of illness or time of access to health services. Information about the quality, safety and performance of health care services is publicly available and accessible to all stakeholders, including elderly people and people with disabilities.

- **Slovakia:** All citizens have access to healthcare services without any discrimination. Discrimination is prohibited in the Slovak Republic and this is true also for healthcare services.
- **Sweden:** The regulations of the Swedish health care system clearly state that there should be equal access to health care. Studies indicate that it is not always the case.
- **Turkey:** Recent reforms have particularly focused on increasing access to health care services for the poor and needy. Since 2004, radical changes have been made to eliminate inequalities in access, with the implementation of both demand and supply-side arrangements. The most important of these was the removal of different accessibility rules between social security schemes and applying the same rules to all of them.

4.1.2 Legal frameworks and policies relevant to health literacy

The survey assessed existing legislation, policies and practices in place to strengthen health literacy. Health literacy was considered a crucial element for strengthening the consultation with citizens, as people first need to be able to process and critically reflect on the health-related information provided to them. Therefore national governments' and Ministries' of Health willingness to create and deliver effective policies and initiatives to strengthen health literacy was considered an important precondition for effective consultation. The survey subsequently appraised the institutional framework in the member states and their governmental programmes, structures, strategies and training opportunities that allowed for health literacy strengthening in a country.

Expectedly, the Ministries of Health were reported to form the main body for the development and implementation of health policy and legislation in the member states. Often it is the Ministry that sets the priorities for health and health care delivery. Any subsequent strengthening of policies and legislation for strengthening health literacy approaches therefore also requires a clear commitment at the Ministry level in order to succeed. Advocates for strengthening health literacy therefore need to see the Ministry of Health as a central authority that needs to be approached.

Depending on the specific national context, additional major players in the member states that were mentioned include health insurance funds, medical associations, medical research councils, the parliaments and their health committees, the national public health institutes as well as regional governments and their public health authorities. Generally, these stakeholders can also exert significant influence on health policy formulation and implementation in the member states. Therefore, they can also act as entry-points for the creation of policies and practices in favor of strengthening health literacy.

4.2 Health Literacy

Different perspectives on health literacy in the member states were assessed by survey questions relating to

- capacity building for professionals
- training and education in general
- training and education for children and young people as well as women in particular
- examples of good practices.

The data provided input to the analysis focusing on the development of health literate populations and health literate organisations/systems. The results are outlined in the following.

4.2.1 Health literate populations

The study illustrated that the **conceptual foundations of health** are provided through formal childhood and adolescent education as well as adult learning programmes. Some notable practices are explained in Box 2.

Box 2: Selected examples for childhood and adolescent education

- **Armenia:** Special educational programmes are performed in schools, universities and other educational institutions to promote a healthy lifestyle.
- **Austria:** The 'health literacy in basic education' project is a pilot project, which integrates health education into the curricula of people who are continuing their basic education at an adult age. This group of people can be considered particularly in need for training in health literacy, as it can be considered a risk group with usually reduced resources.
- **Cyprus:** Health Education is one of the services provided by the School Health Services of the Ministry of Health. It is provided to all schoolchildren of Primary and Secondary Education on various topics, based on an age specific programme, by School Doctors and Health Visitors. Each programme (harmful effects of smoking, puberty, home safety, HIV/AIDS, nutrition, prevention of heart diseases, children rights etc.) is developed centrally at the level of the Ministry of Health. Health Professionals are appropriately trained and relevant material is provided. Health Education is also a subject of the school curriculum provided by the Ministry of Education and Culture. All above programmes aim at empowering school children and require their active participation.
- **Czech Republic:** Within the Framework Educational Programme for Basic Education the area "Humans and Health" exists; this area includes topics such as Health Education or Physical Education. (Health) education is also influenced by other strategies, for example one of the tasks of the National Action Plan of Child Accident Prevention for the years 2007 – 2017, prepared by the Ministry of Health, requires the incorporation of child injury prevention into school curriculum. At present, the accident prevention programme is being prepared also for kindergartens as well. The Framework Educational Programmes for relevant levels of education

Results of the survey on citizens' consultation on the right to the protection of health

define basic requirements on (health) education knowledge and cognitive functions of the relevant age groups and types of schools. The Ministry of Health cooperated with its preparations e.g. by support for children education and young people on healthy lifestyles, prevention of substance abuse, violence and injury prevention, first aid, mental health, etc. According to the Healthcare Services Act N. 372/2011 Coll., as amended, physicians must consider the opinion of children and young people on the method of healing, especially for serious medical interventions (such as chemotherapy or amputation).

- **Finland:** Health education in schools (primary, secondary and high schools) became statutory in 2001. Health education is a subject in primary school, secondary school, and high school.
- **Monaco:** The School curricula encompass the learning of health and hygiene rules through awareness-raising campaigns or school activities enabling health literacy to be acquired.
- **Slovakia:** A State Education Programme was created, which among other topics, also promotes health education as a part of the curriculum of pre-primary, primary and secondary education. It aims to promote life-long health protection and healthcare literacy among students.

Whereas the conceptual foundations of health were widely covered by all respondents, only a few of them referred directly to the **critical skills** in terms of health literacy in a wider context. The examples of notable practices illustrate how health education is being linked to the development of general life skills and emphasis on human development as outlined in box 3.

Box 3: Selected examples regarding the development of critical skills/life skills

- **Armenia:** There is a National Child and Adolescent Health and Development Strategy 2010-2015 and other similar programmes.
- **Austria:** At present, the Federal Ministry of Education and Cultural Affairs plans a revision of the principles of instruction. Health Literacy and Health Education will be considered within these new principles. In 2011, 10 framework targets for health have been developed. One of these targets deals with health literacy for all population groups (including children and young people). Another health target deals explicitly with the health of children and young people stressing also the importance of education and life competencies.
- **Azerbaijan:** There is the State Programme on "Azerbaijan Youth 2011-2015" approved by the President of Azerbaijan Republic dated 07 July 2011. An example is facultative lessons in schools related to Life Skills-Based Education.
- **Germany:** The Federal Centre for Health Education conducts on behalf of the Ministry for Health a variety of interventions, programmes and campaigns for different health problems targeting children and young people. Topics are primary prevention, addiction prevention, programmes on nutrition, physical activity and stress regulation, sexuality education, sexually transmitted diseases and HIV prevention (young adults). All interventions are conducted in close cooperation with local stakeholders and/or regional cooperation partners. The interventions are based on information campaigns and capacity building strategies in order to achieve a better

Results of the survey on citizens' consultation on the right to the protection of health

health competence of individuals or to provide better access to existing services and care structures. The Women's Health Center, Graz promotes health literacy of women and men in several ways: The organisation offers individual health counseling, trainings and workshops to increase health literacy of women and men, provides an online-guide for finding good health information on the internet, sends out newsletters on health literacy and provides evidence based health information and counseling for women.

Few respondents covered the **civic orientation** from a health literacy perspective. The examples of notable practices (Box 4) provide insights in how target groups can be involved in decision-making and influencing content of health initiatives and programmes such as in Austria, where children and young people are involved in the implementation of the child health strategy, and in Israel, where health education is taught as a horizontal cross-cutting issue stimulating children to engage in health across a range of topics.

Box 4: Selected examples regarding the development of civic orientation/citizen engagement

- **Austria:** The Federal Ministry of Education, the Federal Ministry of Health and the Austrian Red Cross finance an information centre for health education in schools conducted by the Austrian Youth Red Cross. The Foundation "Healthy Austria" (Fonds Gesundes Österreich) has supported many projects concerning Health Promotion in schools. Health in all Policies was an important element in the development of national framework targets for health, as well as in the development and Implementation of the National Child Health Strategy. Experts from a variety of areas in the practical field, science and administration have contributed their knowledge, experience and time to bring this strategy to life. Enhancing the life skills of children and adolescents and using education positively as a key factor influencing health are two important goals within the National Child Health Strategy. The Austrian National Nutrition Action Plan and a National Physical Activity Action Plan, which is under development, both consider the special needs of children and young adults. Cooperation with other policy areas and sectors should be strengthened and expanded to implement all these targets with the aim of improving the living conditions, health and Health literacy of children. For example, children and young people are involved in the implementation of the child health strategy through the involvement of representative of youth organisations.
- **Bulgaria:** They are involved through their Regional Health Inspectorates, as well as through specialist within the health cabinets and in the schools.
- **Israel:** The past year was dedicated to Healthy Living in the school system and every school and kindergarten had yearlong activities to promote health. Each discipline (maths, science, history, etc.) had to identify how they could further the health promotion activities in their syllabi (in history they taught the history of health care systems, nutrition and physical activity, in the art class they drew posters of the food pyramid, in the maths class they calculated BMI). In addition, the Director General of the Ministry of Education recently published a directive to all school principals that Health Promotion will continue to be a horizontal subject (across all subjects) for the years to come.

Results of the survey on citizens' consultation on the right to the protection of health

4.2.2 Health literate organisations/systems

The results of the analysis revealed notable practices for the ten attributes of health literate organisations. Selected examples are provided in the following.

The **first** attribute concerning leadership that makes health literacy integral to mission, structures and operations is reflected in the survey with the explanation, that health (literacy) is dealt with at highest level and secured by law and constitution. Mostly designated Ministers for Health, and Education are in charge of ensuring information, training, education and opportunities for engagement of the public in health.

Box 5: Selected examples of health literacy related leadership

- **Israel:** The Israeli government currently has a "Minister responsible for improving the government services to the public".
- **Portugal:** The Ministry of Health, namely the Directorate-General of Health, works in partnership with the Ministry of Education and Science and municipalities in designing and distributing health information.
- **Romania:** Increasing Access to High Quality Primary Prevention Services for Children and Adolescents, 2009-2011, project financed by the Norwegian Cooperation Programme and co-financed by the Ministry of Health of Romania. The project through its four components, research, LIFE campaign, increasing the institutional capacity and legislation improvement, had the aim to increase the number of children and youth with a healthy lifestyle. The Ministry of Health of Romania annually organises and finances several health promotion and education for health campaigns in schools, occasioned by the celebration of international and European health related days. E.g. organization of the campaign "Healthy behaviors for healthy teeth!" occasioned by the International Oral Health Day, aimed to improve the use of effective prevention measures in children, by increasing awareness about the importance of oral health and risk factors.

The **second** attribute focuses on how health literacy is integrated into planning, evaluation measures, patient safety, and quality improvement. The survey had few explicit examples of integration of health literacy into these aspects. However, the following example was given on planning, evaluation, patient safety, and quality improvement in general as exemplified in box 6.

Box 6: Selected example regarding planning, evaluation, patient safety and quality improvement

- **Slovak Republic:** The National Reform Programme 2012 aims to further improve information about the quality of the provided healthcare by creating a list of quality indicators that will evaluate all healthcare providers and the quality of services they provide at least once a year. This list will be made publicly available to inform the patients about the quality of the provided healthcare.

Results of the survey on citizens' consultation on the right to the protection of health

The **third** attribute concerns how the workforce is being prepared to be health literate and monitoring progress. Capacity building was illustrated by a variety of examples. In general, health education is widely taught as part of capacity building, and health literacy specifically, to a lesser degree. The survey showed that health professionals as well as professionals from other sectors are being targeted as illustrated in box 7.

Box 7: Selected examples regarding health literacy capacity building

Health professionals

- **Austria:** Health education is part of the education and training of all high-level health professions in Austria.
- **Cyprus:** Professional training on health education is required background knowledge of all health care professionals.
- **Germany:** The Federal Centre for Health Education (BZgA) was established with the aim of preserving and promoting human health. It was assigned with the tasks to elaborate principles and guidelines concerning the content and methods of practice of health education and to provide basic and advanced training of professionals in the field of health education.
- **Hungary:** In several professions (e.g. health visitors, psychologists) there is a compulsory element of formal education programme concerning health education.
- **Israel:** The Israel Center for Medical Simulation MSR was established in 2001, and is dedicated to improving both medical and human-relation skills of healthcare professionals. One of the things performed are simulation courses in "Communication Skills in Patient-Physician Encounters" for medical students. This is learned through simulation with actors posing as patients with complex scenarios. This is one example of how to try and improve HCPs communication skills. Attending a course like that is mandatory in some medical schools.

Other professionals

- **Austria:** Health education has been embodied as a principle of instruction in the curricula of academic secondary schools and other educational institutions, for all sectors.
- **Belgium:** Primary and secondary schools in Flanders have the obligation to integrate health education in their curricula and programmes of the primary and secondary education. In order to implement this, professional training and material is provided to the teachers.
- **Cyprus:** In service training on health education on various topics is undertaken for health care professionals working at PHC Centers or in the community as well as Professionals working for School Health Services.
- **Germany:** The BZgA has a particular focus on health literacy activities for professionals who are located outside the health sector since individual competencies on health matters are much more shaped by professionals from education and social service sector (kindergarten,

Results of the survey on citizens' consultation on the right to the protection of health

school, social work, leisure time).

- **Lithuania:** According to the requirements of Lithuanian legislation, any professional with the right to provide public health services must attend training courses (including health literacy) of a predefined duration.
- **Monaco:** The promotion of health literacy first and foremost requires both in-service training for medical/psychological/social staff and effective co-operation between numerous departments. Thus training courses helping these staff to provide better support to pupils and answer their questions are run from time to time, for example to update "citizens' first aid" knowledge, or on using a defibrillator. Gradually, other courses are being planned and run on a broad range of issues and covering the whole educational system.

The **fourth** attribute (Box 8) regards how populations served are included in the design, implementation, and evaluation of health information and services. Some countries have more experienced in engaging clients, patients and citizens than others. The format differs from one-time opportunities, to established boards and panels, and hearings.

Box 8: Selected example regarding inclusion of target groups in design, implementation, and evaluation

- **Serbia:** For the past few years, health bazars have been organised in communities to promote healthy lifestyles and the preventive medical services provided by the primary health protection – primary health centres. These events have been performed in cooperation with regional public health institutes and a great number of interested stakeholders in the community in most municipalities.

The **fifth** attribute reflects how the needs of populations are met with a range of health literacy skills while avoiding stigmatization. The survey indicates that several countries are actively targeting hard to reach groups by providing translations and material that is easy to understand. An example is outlined in box 9.

Box 9: Selected example of meeting the health literacy needs of people without stigmatization

- **Hungary:** The TÁMOP governmental programme 2012-2014 implemented by the National Institute for Health Development aims to increase health literacy of the population and specific vulnerable groups.

The **sixth** attribute implies that health literacy strategies are used in interpersonal communication and understanding is confirmed at all points of contact. More and more countries are adapting the user-oriented approach. An example is provided in box 10.

Box 10: Selected example regarding the use of health literacy strategies in communication

- **Portugal:** “Saúde 24” (Health Line 24), an initiative of the Ministry of Health, which aims to meet the needs expressed by citizens in health, helping to expand and improve access to services and rationalize the use of existing resources by routing in a more appropriate way the users towards the National Health Service. It offers screening, counseling and referral in disease situation, accessible via telephone or chat (people with special needs); it also provides therapeutic counseling to clarify issues on matters related to medication.

The **seventh** attribute concerns how easy access to health information and services and navigation assistance are provided. The survey results focus mostly on the legal aspects of equal access, where all respondents refer to the constitution, law and other instruments ensuring the right to access to health. Three respondents questioned whether the equal access is true in practice, and they emphasize that efforts are needed to ensure that the right to equal access to health is protected.

Box 11: Selected examples regarding easy access to health information

- **Austria:** E-card that makes access easier
- **Israel:** The Director General of the Ministry of Health declared that by the year 2013, all medical facilities-professions must be able to provide services in 5 main languages spoken/written in Israel: Hebrew, Arabic, English, Russian, Amharic. This directive will be followed by surveillance and applies to all practitioners and facilities, including signs and written material.
- **Turkey:** Reforms to secure access for disadvantaged population groups.

The **eight** attribute focuses on designs and how print, audiovisual, and social media content is distributed that is easy to understand and act on. The survey reveals that web-based platforms are widely used for sharing information and creating opportunities for interaction.

Box 12: Selected examples of easily understandable and action-oriented communication

- **Austria:** provide the information through a web-based platform.
- **Bulgaria:** has made information public available at websites
- **Cyprus:** has made information public available at websites

The **ninth** attribute regards how health literacy is addressed in high-risk situations, including care transitions and communications about medicines. The data does not cover high-risk situations as mentioned here, but attention is given to hard to reach population groups, who are at particular risk of having limited possibilities in terms of health protection. Some examples are provided in box 13.

Box 13: Selected examples of health literacy as addressed in high-risk situations

- **Austria:** Project "Alpha-Power im Gesundheitsbereich": This pilot project aims to raise awareness and to develop the skills of health professionals for treating people not (sufficiently) competent in the German language.
- **Hungary:** The TÁMOP governmental programme implemented by the National Institute for Health Development aims to increase health literacy of the population and specific vulnerable groups. Starting in 2012 to 2014.
- **Serbia:** Annual conferences on results of quality improvement and patient safety have been organised since 2004. Health care institutions are ranked by agreed criteria. This information is available on the website of the Institute of Public Health of Serbia. Through leaflets and brochures created and published by the Institute of Public Health persons with disabilities and elderly persons have access to information of the quality, safety and performance of Health Care services. Art 27 of the Law on Health Care: Right on information

The **tenth** attribute requires a clear communication on what health plans cover and what individuals will have to pay for services. In this regard, the survey provided little information. An example is identified from Finland, which shows how transparency is prioritized to make choices easier in terms of health services.

Box 14: Selected examples regarding clear communication concerning costs

- **Finland:** The new Health Care Act (1326/2010) sets down the quality of care and patient safety (8 §): Each health care unit shall produce a plan for quality management and for ensuring patient safety. The National Institute for Health and Welfare produces information, available at websites, about accessible health care services and the quality of health care services. There is need to develop and improve coordination on information about available health care services and their quality as a basis for choosing the caregiver.

4.2.3 Challenges and proposed actions for strengthening health literacy according to respondents

The survey included an item referring to challenges regarding the use of the health literacy to strengthen citizen's abilities. Notably, 94% of the national experts 'agreed' or 'strongly agreed' to the statement that health literacy can be used as a concept to strengthen citizen's abilities to make better health decisions in their everyday life. The respondents not agreeing to this statement argued that the lack of knowledge and information on healthy behaviour was not the only reason for unhealthy behaviour. Rather, it was more important to strengthen the determinants of health and the structures and opportunities for living a healthy life and making healthy choices. Important factors that influence decision-making are culture, traditions, education, social and economic status, advertising, habits and others. The experts were asked about the main barriers and facilitators for taking health literacy

Results of the survey on citizens' consultation on the right to the protection of health

strengthening forward at national level. In particular, experts provided an overview of issues that needed to be addressed in order to strengthen health literacy in their countries more effectively⁴:

- Lack of financial resources (4)
- Difficult reach to (migrant) minority groups because of language barriers (3)
- Low quality and accessibility of currently available health information (3)
- No effective tools to motivate and enable citizens to get engaged in projects and programmes (2)
- Rapidly changing information on healthy behavior and health technologies makes it difficult for people to understand (1)
- Some members of society cannot use new communication technologies appropriately (elderly people, functional illiterate people). Reaching them is a specific challenge (1)
- Vested interests by other stakeholders (not further specified) (1)
- Lack of commitment of main actors (politicians in health, education and social affairs, medical professionals, health insurance providers, health care providers) (1)
- Lack of evidence-based methods for information adaptation (1)
- "Health literacy" is a multilayered topic reflecting a lot of professions and their opinions; sometimes even the health professionals are not united in the information on one topic they actively provide the general public with (1)

Accordingly, experts were asked to make proposals or suggestions for strengthening health literacy in their country. The following answers were provided through the survey⁵:

- Increase funding for health literacy (5)
- Introduce health literacy as a relevant (cross cutting) topic in the education system (4)
- Recognize and emphasize the multi-layered and cross-sectoral nature of health literacy (3)
- Cooperate stronger with media to provide good health information (2)
- Improve current health system information and make it more understandable and more accessible (2)
- Include NGOs as partners in the implementation of health literacy actions (2)
- Educate trainers for health literacy (1)
- Systematically link health literacy with prevention measures and activities (1)
- Address key stakeholders to increase political support for health literacy (1)

⁴ Number of responses in brackets

⁵ Number of responses in brackets

Results of the survey on citizens' consultation on the right to the protection of health

- Ensure consistency in information provided to citizens (1)
- Adapt communication to patients' social and cultural background (1)
- Start with health education as early as possible (1)
- Hold round tables, trainings for population and doctors about rights to health (1)
- Establish a National Commission on improving citizens' health, chaired by the highest ranked member of the government and with the vice-chair from an NGO (1)
- Raise the health literacy of politicians who are also citizens, but they also make policies (1).

4.3 Citizens' consultation

The different facets for citizens' consultation in the member states were directly appraised by six survey questions. These items inquired in particular the following dimensions relevant for citizens' consultation:

- Citizens' access to information, including information on quality, performance and safety
- Publicly available and accessible information about quality, safety and performance of health care services
- Communication and consultation with citizens
- Notable examples from the member states

4.3.1 Access to information including information on quality, performance and safety

All respondents to the survey 'agreed or 'strongly agreed' to the statement that citizens have access to information about their benefits and the availability of health care services. The qualitative remarks provided additional insights into the means of communication used to convey this information to the public. The respondents identified the following list of communication tools⁶:

- Websites (11)
- Leaflets & brochures (6)
- Hotlines (2)
- Newspapers and magazines (2)
- Mass media (not further specified) (1)
- Information activities organised by NGOs (1)
- Seminars (1)
- TV (1)
- Patient's rights information unit in hospital (1)
- Personal e-mailing service (1)

⁶ Number of responses in brackets

Results of the survey on citizens' consultation on the right to the protection of health

While this list does not claim to comprehensively cover all available communication channels, the answers showed that the Internet and, more specifically, governmental websites were referred to as being the number one medium to convey information to the public. Some member states have set up web-based information platforms for the sole purpose of informing patients about health care services. Notably, some respondents argued that websites and the internet in general were not the best medium to communicate information, as it excluded elderly people and people without access to internet services. The second most mentioned medium to disseminate information was leaflets and flyers, which were mainly distributed in locations where the patient encounters health care services (e.g. local health institutions and hospitals and their waiting rooms). This was widely considered a reasonable approach, as the people concerned can easily be reached in these facilities. Additional communication tools were mentioned, such as the use of newspapers, information units and personal e-mailing services. The effectiveness of the different channels in communicating information, however, needs to be further investigated.

4.3.2 Public available and accessible information about quality, safety and performance of health care services

The information that is publicly available and accessible in terms of quality, safety and performance of health care services is often provided by most member states on the grounds of their constitutions and laws (see Box 15). However, in some countries this type of information is not provided for public use.

Mostly, the communication is provided through leaflets or e-health services such as web pages from authorities and web-portals. Some countries give the examples of annual conferences on quality and safety. The wide use of e-services means that people without Internet access do not have the same possibilities as people with access to Internet and electronic equipment. This was emphasised by people with disabilities, such as blind people, or elderly with no access or skills to use new technologies. One country mentions the use of specific indicators in the assessment of safety, quality and performance. Another country stresses that although the information is publicly available, the information is rather weak in evaluating or monitoring quality or performance and their subsequent changes. There are concerns in some countries that information provided by the media may not be reliable and that it is the responsibility of governments to inform the public widely in terms of health. On the other hand, one expert argued that although information is available and accessible, there is no proof that citizens are using them accordingly or that they understand their rights given by the written document.

Box 15: Selected examples to ensure publicly available and accessible information about quality, safety and performance of health care services

- **Armenia:** The Constitution of the Republic of Armenia and the Law on Health Care and Services do not distinguish in terms of social classes, and information about the quality, safety and performance of health care services are equally available and accessible for everyone.

Results of the survey on citizens' consultation on the right to the protection of health

- **Austria:** The most important source of information about quality, safety and performance of health care services are delivered by health professionals through a web-based health platform.
- **Azerbaijan:** The Ministry of Health plays a key role through e.g. the Act on "Improving healthcare services for elderly people". The Ministry of Health, in cooperation with the World Bank, has implemented "Health sector reforms" with a focus on monitoring and evaluation.
- **Bulgaria:** Information about health care services is publicly available on the websites of the respective bodies/entities.
- **Cyprus:** Health care information is provided to everybody without any discrimination. The information about the quality, safety and performance of healthcare services is publicly available on the website of healthcare providers.
- **Finland:** The new Health Care Act (1326/2010) sets down the quality of care and patient safety (8 §): Each health care unit shall produce a plan for quality management and for ensuring patient safety. The National Institute for Health and Welfare produces information, available on websites, about accessible health care services and the quality of health care services. There is a need to develop and improve coordination on information about available health care services and their quality as a basis for choosing the caregiver.
- **Lithuania:** Most of the information about the quality, safety and performance of health care services is available online, through various networks etc. Information is available on the websites of the Ministry of Health, the State Health Care Accreditation Agency under the Ministry of Health, and on the websites of health care providers.
- **Moldova:** On the approval of the single compulsory medical insurance programme, the National Health Insurance Company collaborated with local authorities and health care providers to organise campaigns which familiarise people with the amount of healthcare assistance foreseen by the Single Mandatory Health Insurance Programme.
- **Serbia:** Annual conferences on results of quality improvement and patient safety have been organised since 2004. Health care institutions are ranked by agreed criteria. This information is available on the website of the Institute of Public Health of Serbia. Through leaflets and brochures created and published by the Institute of Public Health, persons with disabilities and elderly persons have access to information on the quality, safety and performance of health care services. Art 27 of the Law on Health Care: Right to information
- **Slovak Republic:** The National Reform Programme 2012 aims to further improve information about the quality of the provided healthcare by creating a list of quality indicators that will evaluate all healthcare providers and the quality of services they provide at least once a year. This list will be made publicly available to inform patients about the quality of the provided healthcare.

4.3.3 Communication and consultation with citizens

This part of the survey addressed the questions to what extent citizens were able to have free access to information and care in the respective member states and to what extent they were able to voice their

Results of the survey on citizens' consultation on the right to the protection of health

opinions and complaints about the health care system. The survey assessed the existence of complaints mechanisms for patients. These mechanisms can serve as channels for the public to voice their opinion and to be heard. As such, it fulfills an important function in any consultative processes for citizens. 95% of the respondents to the survey stated that complaints mechanisms were in place in their countries. The main mechanisms mentioned in the survey were⁷:

- Complaints commissions (9)
- Specifically created institutions / units / investigators (6)
- Telephone hotlines (5)
- Ombudspersons (4)
- Patient representatives (3)
- National mass media (1)
- 'Health lawyers' (1)
- Complaint forms (internet) (1)
- Complaint books (1).

While this list is by no means exhaustive, it provides an overview of the possible approaches to setting up complaints mechanisms. Mechanisms can be very informal with a low threshold (e.g. telephone hotline) or very structured complex and legally binding (e.g. independent institutions with a mandate to deal with quality control and complaints in the health sector). The choices for the different complaints mechanisms were largely based on the reported context at hand. Nevertheless, countries can be encouraged to review their own complaints mechanisms and may consider taking up additional mechanisms as outlined in this list. In addition to the complaints mechanisms, all member states reported that in general, patients were able to freely express their opinion on the health care services provided. All respondents either 'agreed' or 'fully agreed' that this was possible. Many of the tools available to the citizens to voice their opinion have already been listed in the aforementioned complaints mechanisms: patient representatives, telephone hotlines, social media websites and the media in general were often referred to as relevant channels through which citizens voiced their opinion on certain issues. Box 16 presents a selection of practices, including both complaint mechanisms as well as general feedback channels.

Box 16: Selected examples of channels for citizens to voice their opinion (including complaints mechanisms)

- **Austria:** Patient advocacies (patient representations) are operating in each of the nine Federal States. They are established based on the regional State Acts and they are responsible for all the hospitals of the Federal State and for all the patients treated in these hospitals. Their major task is to represent patient interests and rights. They offer free legal advice in the area of patient rights as well as free extrajudicial procuration in case of suspicion of errors in treatment.

⁷ Number of responses in brackets

Results of the survey on citizens' consultation on the right to the protection of health

- **Croatia:** Every Wednesday, the Minister of Health meets with representatives of health-related NGOs (such as Coalition on Health, Patients' rights organisations, etc.) to discuss health service and health system related matters.
- **Cyprus:** A Complaint Review Committee is in place. The mission of the Complaint Review Committee is the effective monitoring and ensuring of the rights of any person addressed by any health care provider or medical institution, including the private sector. The main goal is for these committees to become participants and contributors to change in the effort to rebuild the health system and to upgrade the quality of services to the citizen.
- **Czech Republic:** All health care establishments have a patient ombudsman, who informs patients of their rights and assists them as necessary in submitting an objection or complaint concerning treatment, or a claim for indemnity for professional negligence.
- **Finland:** If a patient or next of kin is unsatisfied with the patient's medical care or treatment, he/she can complain to authorities responsible for health care supervision in Finland. This procedure is available to all health care or medical care patients in Finland regardless of the patient's citizenship.
- **Germany:** A Commissioner of the Federal Government looks after patients' issues. The tasks of the Patients' Commissioner are to ensure that the issues of patients, particularly with respect to their rights on extensive and independent consultation and objective information by service providers, cost units and authorities in the health care sector and regarding participation in questions of ensuring medical care, are considered. For the realisation of this task the federal ministries offer the Commissioner participation in all legal, regulatory or other important initiatives as far as rights and protection of patients are concerned or touched upon.
- **Hungary:** There is a network of independent Patients' Rights Representatives (PRR) in every health care institution. The institutions have a legal obligation to employ such a PRR.
- **Serbia:** Through the DILS project (Delivery of improved local services) of the Ministry of Health, financed by the World Bank, nine lawyers at the local level are being educated in the field of protection of patients' rights. By the end of the project, the number is expected to increase to 42.
- **Serbia:** Patients can send complaints to the head of department in the respective health institution and to the Protector of patients' rights, a position; which exists in each health institution. He/she can voice his/her opinion to the health inspection and directly to the Ministry of Health. The complaints can be also sent to the Ombudsperson.
- **Serbia:** A survey on patients' satisfaction is carried out in each health institution once a year.
- **Slovak Republic:** The majority of healthcare providers have a dedicated way for citizens to submit ideas for improvements (email address, book of complaints). If not, citizens can contact their health insurance company in this matter.
- **Sweden:** The Instrument of Government (Regeringsformen) is the fundamental law in Sweden and guarantees every citizen freedom of expression; the freedom to communication, information and express ideas, opinions and sentiments whether orally, pictorially, in writing or in

some other way. All citizens are also free to express their views on the public health and medical care, directly to the County Council or the municipality. Some municipalities have a specific Public Health and Medical Services Committee.

- **Sweden:** There are several complaint mechanisms available for patients in Sweden. A complaint about poor treatment in health and medical care can be made to the Patient's Advisory Committee, which is situated in every County Council. The role of the Patients' Advisory Committee is mainly to support and assist individual patients in obtaining the information they need to look after their interests and help them in determining which public authority to turn to.
- **Turkey:** SABIM (Patients Hotline of the Ministry of Health) was established in 2004 to identify problems in the health care system and solve them immediately on site and in the fastest way possible. Calling the phone number of SABIM (184) for a problem occurred in any process of the health care system activates an auto-control mechanism. An application recorded by SABIM Operators is sent to related provinces SABIM after being evaluated by SABIM Analysers. This application is analysed in the most accurate way by SABIM Analysers immediately.

4.4 Ten notable practices from member states regarding citizens' consultation

Based on the survey results and additional literature provided by the involved stakeholders, various practices for consultative mechanisms were identified by the member states. The reported practices were reviewed and a selection of 10 examples is included in this report. These 10 practices were chosen in the context of the framework developed by Patterson Kirk Wallace, which differentiates between five levels of involvement (see chapter 2, figure 3). Accordingly, the 10 practices were chosen to serve as examples for these five levels of involvement. Furthermore, we meant to provide examples for citizens' consultation from both sectors: health care and health policy processes.

Level 1: Inform or educate

1. Israel – Health information through an online portal

One mechanism to improve the public's access to information of health related rights is a Wiki-type website called "Kol Zchut" (www.kolzchut.org). Kolz Chut means "All rights" and the website includes information about the rights of citizens in all matters including health related issues. The Israeli government currently maintains a Minister who is responsible for improving the government services to the public - and this office endorses and encourages other Ministries to assist the NOG responsible for this website in its actions. The website is written in easy language (mostly in Hebrew, but also in process of translation into Arabic and English). It aims to be easy to understand and has many links directing to relevant pages and documents (forms, information sheets, rules and regulations) on other websites such as ministries, HMOs, hospitals and other health services and providers.

2. Turkey

3. The telephone hotline "SABIM" was established in 2004 to identify problems in the Turkish health care system and to solve them immediately on site and in the fastest way possible. Anyone from Turkey can call the SABIM hotline and can provide information on any kind of problem or question regarding the health system. Operators responding to the calls are health professionals, who have comprehensive knowledge of the way the health system functions, with sufficient knowledge on health legislation. The operators do not only provide answers and solutions to the problem, they also keep records of any kind of questions, problems, criticisms, suggestions and requests. Citizens can use SABIM for the following issues:

- Information on any matter related to the functioning of the health system
- Submission of requests, criticisms and suggestions about the health system
- Conveying of problems they face at any stage of the system while making use of health services.

Level 2: Gather information

4. Austria – citizens' consultation in the health target process

The Austrian government decided in 2012 to introduce 10 health targets for Austria. These were developed by the so-called 'Bundesgesundheitskommission' (Federal Health Commission), the highest political body for health policy in Austria. This body consists of representatives of the national, regional and local governments, social insurances, health care institutions as well as patient and doctor's representatives. Notably, the development of the health targets was based on a consultative process with citizens. Through an online platform, citizens were invited to voice their opinion on the content of the health targets. Between May and August 2012, almost 4500 citizens participated in this process. The answers and viewpoints were collected, appraised, discussed and ultimately used for the development of the 10 Austrian health targets.

5. United Kingdom (England) – citizen participation in health care decision making (taken from: Prognos, 2011)

In 2001, the Health and Social Care Bill was introduced which legally regulated patient and citizen participation in England. Since then, the National Health Service (NHS) has been obliged to involve the public, and the public is regularly consulted on various health related issues. An overview of current and past consultative processes initiated by the NHS, please refer to:

<http://www.dh.gov.uk/health/category/latest-publications/consultation>

6. Germany – Citizen involvement in appraisals of care and treatment options (taken from Prognos, 2011)

The Institute for Quality and Efficiency in Health Care (IQWiG) is a nationally-funded scientific institute that appraises the benefits and harms of medical interventions for patients. The institute provides evidence-based reports on topics such as: drugs, non-drug interventions, methods for diagnosing and

Results of the survey on citizens' consultation on the right to the protection of health

screening, treatment guidelines and disease management programmes (IQWiG, 2012). By law, the IQWiG needs to give the following groups the opportunity to submit comments on their reports: medical, pharmaceutical and health economic experts from research and practice, pharmaceutical manufacturers, the relevant organisations responsible for representing the interests of patients and self-help groups of chronically ill and disabled persons, and the Federal Government Commissioner for Patient's Affairs (Prognos, 2011).

Level 3: Discuss

7. The Netherlands – Council for Public Health and Health Care (Taken from Prognos, 2011)

The Raad voor de Volksgezondheid en Zorg (Council for Public Health and Health Care) is an independent body advising the government on public health and care. The body consists of nine members appointed by the government. The members are not official representatives of any organisation and the consideration of patient interests depends on the chairperson. The Council provides advisory reports on various issues. Each advisory report is prepared by one or two members of the Council, supported by a project team from the Secretariat and then presented to the Council for adoption. The Council may also consult external specialists, both from in- and outside the health service. Patients are involved in the preparations of these advisory reports, for instance in the committees and background groups, and collective patient interests are always presented to the Council. There are formalised relations to the Dutch Patient and Consumers Federation (NPCF), the Council for Disabled People and the Dutch Consumer Association as well as to disease-specific patient groups. The NPCF usually publishes a press release after the publication of an RVZ advisory report. Participation is not a formal requirement. Moreover, relevant organisations and stakeholders are invited to participate, where and when considered necessary for the topic at hand.

Level 4: Engage

8. Sweden: Citizen involvement in the National Board of Health and Welfare (taken from Prognos 2011)

The National Board of Health and Welfare (Socialstyrelsen) is a government agency under the Swedish Ministry of Health. Its main activities concern the compilation and analysis of health care information, the development of standards, monitoring the observation of standards, as well as maintaining health data registers and official statistics. In 2008, the Socialstyrelsen has created a committee to advise the General-Director on different issues the agency has to deal with (Prognos, 2011). In order to ensure a broad democratic basis, the government considers different interest groups (like patient groups), professions and political parties to be part of this committee. Formal membership. Further mechanisms ensure an input of patient and other interest groups in this advisory committee.

9. France – citizens as equal partners in decision making (taken from Prognos, 2011)

The “Haute Autorité de Santé” (HAS) is an independent scientific body that provides health authorities with the information needed to make decisions on the reimbursement of medical products and services. Furthermore, it is responsible for the improvement of the quality of care in health care organisations and in general medical practice and to promote cooperation between the relevant stakeholders. Patient representatives are involved in the advisory bodies and contribute their knowledge as members of the steering committee and working groups (surveys, elaboration of observations, documents) as well as members of the review group. Notably, patient representatives have the same rights and obligations as other stakeholders within the HAS; this also covers voting rights. For this reason, patient representatives must be involved before a decision can be taken. With regard to reviews, the responsibility lies with the individual working groups to decide how changes proposed by patient representatives are justified and if they should affected groups can be asked to participate.

10. Denmark: No distinction between consumers, physicians and pharmacists in councils to discuss effects of medicine

The Danish Medicines Agency (Lægemiddelstyrelsen) is an agency under the Ministry of the Interior and Health. Its aim is to ensure that medicinal products in Denmark are of good quality, are safe to use and that they have the desired effect. To do so the agency administers the Danish legislation on medicinal products, reimbursement, pharmacies and medical devices. In doing so, it is advised by several committees and councils consisting of experts and stakeholders. One of these councils is the so called ‘Bivirkningsrådet’, which comprises representatives of industry, therapists, patients and consumers. As of July 2011, several patient and consumer representatives were members of Bivirkningsrådet, including the Parkinson Society, the Danish Consumer Council and the Organisation for Danish Patients) (Prognos, 2012). The meetings’ minutes are published on the website and also list the names of the attendees or announce the next scheduled meeting. Furthermore, each council member has to answer a questionnaire. The latter is also published on the website.

Level 5: Partner

11. Germany – Public dialogue since 1991. Health Conferences in the State of North-Rhine Westphalia

The Health Conference (Gesundheitskonferenz) discusses and decides annually on resolutions and common targets to improve health in North-Rhine Westphalia. Different actors and stakeholders from the health and social welfare system come together on an annual basis to discuss and agree on common goals with the government. One of the main reasons for the creation of the Health Conference was to create a forum in which actors could engage in cooperation, consensus finding and trust building. Furthermore, the Health Conference was viewed as a governance mechanism to deal with the multiple actors in a largely self-governed health care system. The Health Conference involves a broad spectrum of stakeholders. Chaired by the Ministry of Health, the Conference includes patients’ and

Results of the survey on citizens' consultation on the right to the protection of health

doctors' associations, welfare and labour organisations, representatives from hospitals and sickness funds.

5 Discussion and recommendations

Consultation processes have been considered a vital element of good governance and of modern democracies. Therefore, it can be viewed as a good element to promote and strengthen the objectives of the Council of Europe, which are to protect and promote human rights, pluralist democracy and the rule of law. The protection of health and the public consultation processes are important values for the Council of Europe and its member states.

The Survey investigated mechanisms for both health literacy and citizens' consultation at member state level. In doing so, the goal was not to provide a comprehensive and systematic review of all processes in the member states. This was not possible due to the constraints in time and resources. The idea was rather to develop a survey with a non-exhaustive character, which allows for a rapid appraisal to identify interesting practices and provided entry points for subsequent evaluations.

5.1 Reflection on Health literacy findings

The results of the health literacy analysis provide a fruitful insight in how member states work to improve the health literacy in populations and within systems. With regard to health literacy in populations health education has been institutionalised and forms part of formal education and life-long learning creating a profound basis for the development of health literacy in populations. However, most emphasis is given to the conceptual foundations, and less to the critical skills and civic orientation forming part of health literacy. Information and awareness raising were the most dominant approaches, and less emphasis was given to interaction and engagement of citizens, whether children, students, women or people at risks. The initiatives were most often described with a top-down approach, rather than a people-centered approach, and could rather be interpreted as being made *for* people involved, less than *with* people involved. The analysis regarding health literate systems illustrates that there is a pull towards improving the systems to be more health literate and that capacity building is taking place involving both health professionals and professionals from other sectors including a focus on health literacy. The survey showed that both governments and NGOs take on leadership roles in promoting health literacy, and structures are being established which integrate health literacy as a value. Yet, it was also mentioned that though structures, guidelines and laws are in place or being developed to secure health protection and the advancement of health literacy, they may not always reflect the reality and some parts of the population may be less well off than other parts. Although notable practices are found for all ten attributes relevant for health literate organisations, they are not many and not very elaborated. The area is clearly under development and the field is not as institutionalised as seen with reference to health education provision. The study shows that member states are prioritising the area and countries such as Austria and Israel are frontrunners providing numerous examples on how health literacy can be strengthened.

Results of the survey on citizens' consultation on the right to the protection of health

The current study shows how formal, comprehensive health education programmes are being organised as part of formal education reaching out to the wider part of the population. Yet, the European Health Literacy Survey shows 47% on average in eight European countries to have limited health literacy, which makes it difficult for people to access, understand, appraise and apply information to take decisions concerning their health in daily life (HLS-EU Consortium, 2012). The discrepancy between what is offered through educational programmes and the apparent lack of competencies raises the question on what can be done to secure a better match. On the one hand, the left side of the balance needs to be supported with more opportunities for people to develop their critical skills and engage through civic partnerships in health. On the other hand, the right side of the balance needs to be supported by increasing the ten efforts that can ensure that systems are equipped to comply with people's needs and match their levels of health literacy. Opportunities should be provided to ensure stronger consultations with clients, patients and people in general to facilitate better and more appropriate services. When the two sides are aligned, quality of communication and actions are likely to be enhanced from both sides involved.

5.2 Reflection on citizens' consultation findings

The results of the survey provided insights on the approaches that were used to consult with citizens in the member states. In addition, the findings were linked to a conceptual framework, which differentiates five different levels of citizens' consultation. The underlying rationale of this framework is that scaling up citizens' consultation to the higher levels would be important and beneficial for all stakeholders involved. Despite the fact that the ten presented cases provided examples for all five levels of the framework, it should be pointed out that the initial survey responses mainly referred to the levels 1 (inform and educate) and 2 (gather information). Citizens and patients were legally entitled to information about health care and health policy processes and the survey respondents reported various communication channels through which information was publicly available. Furthermore, citizens were also able to voice their opinion and their discontent (complaints) if unsatisfied with ongoing processes through various complaints mechanisms. However, the levels 3 to 5 were largely not covered by the survey items. This is despite the fact that citizens' consultation unfolds its full potential at these levels. Only through discussions (level 3), engagement (level 4) and partnerships (level 5), health care and health policy processes can be actively shaped and supported by citizens. However, this often requires a more substantial change in current systems and procedures and the feasibility of implementing consultative processes at these levels requires a careful analysis of available capacities and willingness to support the process. Although we were able to identify notable examples for these levels, it should be acknowledged that the information was fairly limited. A more systematic appraisal of the effectiveness and efficiency of existing consultation platforms, including the levels 3-5 would be beneficial.

5.3 General reflections on the survey results

Bearing in mind that the study approach was a quick-scan of the current situation in member states the study results are by no means a comprehensive view of how member states execute citizens' consultations and invest in health literacy. It has its limitations as e.g. countries believed to excel in both areas may not have taken part in the current survey. Additional input to the survey was provided at the Workshop in Strasbourg in November 2012 and from literature. The quantitative data was very homogenous for many items, which made it difficult to distinguish differences among the countries. The qualitative data was in some items not as saturated as aimed for. In spite of the limitations, the dataset provided useful insights into the streams of developments within the field of health literacy, citizens' consultations and the overall efforts to protect citizens' health.

The main conclusion of the report is that member states are prioritising the health of citizens and they are shifting towards a people-centered approach. The change process reveals some countries to be frontrunners with numerous examples of initiatives including health literacy strategies and engaging partnerships. Yet, other countries are in a time of transition, where initiatives can still be characterised as top-down, with a focus *for* people, rather than *with* people. The notable practices on health literacy included in the report entail examples of country activities concerning building the conceptual foundations, as well as the enhancement of critical skills and civic orientation, which are fundamental to the active partnerships wished for in the implementation of strategies regarding citizens' consultations. In addition, it was possible to identify examples of the ten attributes of health literate systems and organisations, which indicate that health literacy is becoming a strategic value in the future. The ten notable practices on citizens' consultations in particular emphasize the need to be more proactive in the facilitation of levels three to five in terms of discussion, collaboration and establishment of partnerships. The trends shown in the survey point towards a steady growth towards a more inclusive European society with regard to protecting people's health.

5.4 How could citizens' consultation be taken forward in member states of the Council of Europe

The final question of the survey asked respondents to share ideas on the Council of Europe's plans to create a Citizens' Consultation Platform on the right to the protection of health. Generally, the idea of developing such a platform was positively perceived by the respondents and some deliberately applauded the initiative. However, practical suggestions about how such a platform should be developed were scarce. This can be attributed to the short time frame in which the respondents needed to complete the survey and complexity of the subject. Nevertheless, the survey did manage to extract information, which could feed into a process to develop a template for citizens' consultation in the member states of the council of Europe.

Results of the survey on citizens' consultation on the right to the protection of health

The survey implicitly showed that the member states of the Council of Europe have different political, cultural and economic backgrounds. These differences are also reflected in the currently existing consultative processes, which automatically influences the prospects of developing effective and efficient consultative processes in the future. The specific context of each member state therefore plays a decisive role and considerations needs to be made on a case-by-case basis whether consultative processes are feasible and realistic in terms of human and financial capacities and political will. The role of the Council of Europe should be to act as an intermediary that fosters cross-national learning and the exchange of good practices. Through commissioning the survey and this report, the Council of Europe has already taken up this role. Furthermore, the Council of Europe foresees to develop and pilot a Model of a Citizens' Consultation Platform on the right to the protection of health. To develop such a model, the Council of Europe should build on the well-established expertise of researchers, organisations and member states, who have previously worked on this topic. Potential entry points for a review of existing information could be the work performed by OECD, in which a set of 10 golden principles for citizens' consultation are presented (OECD, 2001). Further, Abelson et al. (2001) provide a practical review of public participation methods. In their review, they provide insights into strengths and weaknesses of the different mechanisms and give recommendations for their subsequent use. Despite the fact that both of these documents are more than a decade old, they still provide very rich insights into how to develop and implement citizens' consultation platforms.

Additional authors and organisations have developed *frameworks* or *guidelines* that can be applied for citizens' consultation. A few examples of this include the Public Consultation Framework from the Irish Health and Social Care Regulatory Forum (2009), the Forster-Matrix for participation in the health system presented by Prognosis (2011) or the Code of Good practice from the Council of Europe's Conference of International Non-Governmental Organisations (INGOs) (2009).

The general recommendation is that a subsequent development of a framework should build on existing work in order to avoid overlap and duplication of efforts. Due to the diverse nature of the Council of Europe's member states, a model needs to be flexible in order to be able to be applied in all member states. After the development of such a model, it should be piloted in some countries on particular issues where citizens' consultation would be beneficial. In this way, the model could be tested for its practicability and could be adjusted accordingly. As such, the model will serve as vehicle and leverage for the ongoing efforts in the field.

6 References

- Brach et al., 2012. Ten Attributes of Health Literate Health Care Organizations. Discussion Paper. Institute of Medicine.
- Council of Europe, European Social Charter (Revised), 3 May 1996, ETS 163, available at: <http://www.coe.int/t/dghl/monitoring/socialcharter/Presentation/ESCRBooklet/English.pdf> [accessed 18 October, 2012].
- Council of Europe, 1997. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, available at: <http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm> [accessed 06 November, 2012]
- Council of Europe Recommendations:
- CM/Rec (1997)17 - Recommendation on the development and implementation of quality improvement systems in Health care
- CM/Rec (2000)5 - Recommendation on the development of structures for citizen and patient participation in the decision-making process affecting health care. Council of Europe Publishing, Strasbourg.
- CM/Rec (2000)13. Recommendation on criteria for the development of health promotion policies. Council of Europe Publishing, Strasbourg.
- CM/Rec (2006)7- Recommendation on management of patient safety and prevention of adverse events in Health care
- CM/Rec (2010)6 – Recommendation on good governance principles in health care systems
- CM/Rec (2012)8 - Recommendation on implementation of good governance systems in health care systems
- Conference of the INGOs of the Council of Europe (2009). Code of good practice for civil participation in the decision-making process. Strasbourg. Available at http://www.coe.int/t/ngo/Source/Code_English_final.pdf [accessed 27 November 2012].
- Freedman et al., 2009. Public Health Literacy Defined. May 2009 Am J Prev Med; 36(5) 449
- Health and Social Care Regulatory Forum. (2009). Health and Social Care Regulation in Ireland. Available at: <http://www.rpii.ie/RPII/files/62/62f874c3-65e6-4b93-b923-695a3c8ba9bf.pdf>. [accessed: 27 November 2012].
- Health Care Quality Improvement Partnership. (2009). Patient and Public Engagement (PPE). Available at: <http://www.hqip.org.uk/assets/PPE/HQIP-PPE-Guidance.pdf> [accessed: 27 November 2012].
- HLS-EU Consortium, 2012. Comparative report on health literacy in eight EU member states.
- IQWiG. Institute for quality and efficiency in health care, 2012. Responsibilities and objectives of IQWiG [website]. Available at: <https://www.iqwig.de/about-us.21.en.html>. [accessed 26 November, 2012].
- Kickbusch et al., 2006. Navigating health: the role of health literacy. Alliance for health and the future. International Longevity Centre. UK
- Nutbeam, 2000. Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. Health Promotion International; 15: 259–67
- OECD, 2001. Engaging citizens in policy-making: Information, Consultation and Public Participation. Puma Policy Brief No. 10. Available at <http://www.oecd.org/gov/2384040.pdf>. [accessed on 27 November 2012].
- Parker & Ratzan, 2010. Health literacy: A second decade of distinction. Journal of Health Communication, 15:2
- Prognos, 2011. Patient and citizen participation in health care systems. Good practice in selected health care systems. Available at: http://www.prognos.com/fileadmin/pdf/publikationsdatenbank/2011-10-26_vfa_PhRMA_Report_English_final.pdf. [accessed on 19 November 2012].

Results of the survey on citizens' consultation on the right to the protection of health

Rowlands et al., 2012. Health literacy and public health: a framework for developing skills and empowering citizens. *Perspectives in Public Health*, 132:23

Sorensen et al., 2012. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, 12:80

Appendix 1

Countries that participated in the survey

Armenia
Austria
Azerbaijan
Belgium
Bulgaria
Croatia
Cyprus
Czech Republic
Finland
Germany
Hungary
Israel
Lithuania
Moldova
Monaco
Norway
Portugal
Romania
Serbia
Slovak Republic
Sweden
Turkey