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COUNCIL OF EUROPE

MODEL OF A CITIZENS' CONSULTATION PLATFORM ON THE RIGHT TO THE PROTECTION OF HEALTH

by

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Introduction

With the publication and adoption of the European Social Charter in 1961, the Council of Europe made a historic step towards creating a unified approach towards the attainment of the conditions for the realization of several rights and principles. As such, the European Social Charter served as an enabler for widespread changes amongst the Member States, leading to many positive measures taken to improve the social situation of many citizens.

The revised European Social Charter, adopted in 1996, aims to encourage Member States to achieve the right conditions through which numerous rights and principles may be realized. The Charter clearly puts the onus on Member States to establish and maintain the conditions necessary to realize the rights and principles listed in the Charter.

One of the important pillars of the Charter is the citizens' right to the protection of health and over the years much discussion has taken place concerning the implementation of measures designed to enable citizens to attain the highest standard of health.

This paper proposes a new model for citizen consultation on one of these rights listed as follows in the Charter: 'everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable' (Article 11).

The measures are broken down into three areas:

- Remove (insofar as possible) the causes of ill-health (Protection)
- Provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility (Promotion)
- Prevent (insofar as possible) epidemic, endemic and other diseases, as well as accidents (Prevention).

Member States have already taken many measures to enable their citizens to attain the highest possible standard of health. For example, Member States have taken effective action to combat and eradicate highly infectious diseases such as polio. However, the effects of many other measures remain unknown and many more measures need to be implemented in order for the highest possible standard of health to be achieved.

As stated in the Council of Europe's New Strategy for Social Cohesion (2010, page 3) 'an increasing number of people face obstacles to the full enjoyment of rights'. These obstacles or barriers to the full enjoyment of rights pose one of the greatest challenges to social cohesion.

One of the ways to help overcome the obstacles is to engender a sense of community awareness and a shared responsibility. The underlying argument is that health outcomes improve when people become actively involved and participate in the decision making process over their own health and contribute to the health of their community.

Recent research (Øvretveit, 2012) supports this notion and there is evidence of negative health consequences for patients when health professionals failed to sufficiently consider patients’ preferences and lifestyle and also when they did not agree assessment and

treatment plans in a collaborative way. On the other hand, there are also interventions and changes to promote patient–professional communication and collaboration to bring about a more active role for patients and to support self-care. However, these solutions are not simple, they can be costly, have not always been proven to work and implementation may require considerable time and attention.

To support the implementation of the measures by Member States aimed at achieving a higher standard of health for its citizens, the Council of Europe has decided to concentrate some of its activities on improving citizen participation in healthcare and creating a sense of shared responsibilities.

Therefore the aim of this paper is to propose a model platform for effective citizen consultation on the prevention of ill health and the protection and promotion of health. The assumption being that consultation is one of a range of key measures Member States can take to enable citizens to enjoy the highest possible standard of health attainable.

Terminology used

By developing and promoting the model platform of citizens' consultation on health, the Council of Europe intends to assist Member States to take appropriate measures to protect citizens' health, to promote healthy lives through education and awareness raising and to prevent diseases.

In the first place, it is important to define what is meant by the different terms used in order to create greater clarity and establish a better, common understanding.

Consultation with citizens regarding healthcare can be considered a patient-focused intervention since it recognizes the role of patients as active participants in the process of achieving high quality healthcare. The Institute of Medicine (IOM) defines patient-centered care as: Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care (IOM, 2001).

At the request of the UK-based Health Foundation, two experts from the Picker Institute Europe, Angela Coulter and Jo Ellis reviewed the evidence behind these so-called 'patient-focused interventions' (Coulter & Ellis, 2006). The authors proposed the following classification of 'Patient-focused interventions', based on the understanding that patient-focused interventions are generally aimed at one or more of the following seven quality improvement goals:

- Improving health literacy
- Improving clinical decision-making
- Improving self-care
- Improving patient safety
- Improving access to health advice
- Improving the care experience
- Improving service development.

Each goal is subdivided into specific measures and within the last goal (Improving service development) the authors categorize the following measures: Consultation; Patient Participation in Groups and Lay Representation (i.e. patients represented at Board levels for example).

The authors (Coulter and Ellins, 2006) make a distinction between public or citizen involvement and patient involvement. According to the authors, public or citizen involvement refers to the ways in which citizens can take part in the decision-making process regarding the management, development, planning and provision of health services. This is different from patient involvement, which is concerned with the contributions that people can make to decisions about their own treatment and care.

This classification can be helpful as the report (Coulter and Ellins, 2006) also refers to the scientific evidence for the effectiveness of each measure. The authors conducted a thorough and systematic review of the available evidence and the table below gives a short summary of a selected number of measures.

Category	**Measure (example)**	**Summary of evidence**
Improving health literacy	Information given to patients in a personalized format	Evidence suggests recall and knowledge is most improved with personalized information.
Improving access to health advice	New modes of healthcare professional-patient communication	Telemedicine and outreach measures have been shown to improve patient access somewhat and reduce travel times and out-of-pocket costs. However, when compared to the more traditional model of care, no significant cost difference could be found.
Improving the care experience	Open and transparent sharing of information about the quality of healthcare (Public Disclosure)	Research has found that, even though patients often want information on quality, in many instances patients do not use the information to make decisions about their healthcare. However, evidence exists indicating that public disclosure has a positive overall effect of the quality of care provided.
Improving service development	Public consultation	People reported that they welcomed opportunities for involvement, and these can increase participants' self-confidence, self-esteem and levels of social contact.

Consultation with citizens on the right to the protection of health can be described as engaging and involving individuals as citizens. This is not necessarily the same as engaging with individuals as patients (or patient involvement) as the latter can be described as involving patients in making decisions about their care, whereas the former as citizen or public involvement.

In the literature there are two rationales given as to why it is important that citizens can participate in decision making. Two main approaches can be identified: the democratic and consumerist approach. The consumerist approach reflects economic theories that argue that participation gives citizens a voice because they have information enabling them to make better choices. The alternative theory is a democratic approach which argues that participation leads to more democratic decision-making.

Citizens can participate in decision making in different ways, at different levels and at different times. In 1969 Sherry Arnstein developed a ladder (see Appendix 1) to describe the levels of participation (Arnstein, 1969). Arnstein describes participation from the lowest level (manipulation, information giving) to the highest level (citizen control). The mechanism at

the lower level of the ladder offer citizens little opportunity to genuinely influence and shape decisions, whereas at the higher end of the citizens have far greater influence over the decision making process through measures such as partnership, delegated power and citizen control. According to the author, citizen consultation is somewhere in the middle of the ladder.

However, since Arnstein proposed her ladder of levels of participation, a number of alternative conceptual models have been developed that argue that there should not be a hierarchy (or rungs of a ladder) in terms of who is in control. Instead, authors such as Tritter and McCallum (2006) argue that it is important to realise that patient participation is more dynamic and has numerous different participants.

Impact of citizen consultation

As stated before, there appears to be a consensus emerging amongst various stakeholders, including the Council of Europe, the European Commission and the World Health Organization, which improved citizen (patient) involvement in healthcare, will ultimately support the attainment of better health outcomes. In this section, we will take a brief look at some of the evidence in support of this notion.

Over the last couple of decades, in many countries healthcare has begun to evolve from 'doctor-led care' to 'patient-led care' (Agency for Healthcare Research and Quality, 2002). Part of this evolution is the move from a focus on the diseases with doctors making the majority of the decisions to a model that involves and empowers patients. This shift in focus is due to the understanding that healthcare can only reach the highest standards if it is organised around and is responsive to the needs of the people using it.

Many Member States have taken measure to improve their healthcare systems by supporting this shift and taking steps to focus on the needs of the citizen rather than the needs of the system. Due to the better access to information, citizens have also become more informed about their own health needs and the healthcare options available to them.

At an international level, these measures are supported by strategic policy documents such as the World Health Organization's Ljubljana Charter (1996), which advocates for more emphasis on citizens' participation and consultation and the World Health Organization's Declaration of Alma-Ata (1978) which states that “The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare” (clause IV).

However, challenges such as non-adherence to medical advice and medications remains a recurring problem, with reports of as many as 25% of patients who do not follow medical recommendations (DiMatteo, 2004, as quoted in Øvretveit, 2012) and 25% non-adherence to the medications prescribed (Claxton et al, 2001, as quoted in Øvretveit, 2012).

There is scant evidence to suggest that public involvement or indeed consultation has made an impact on the attainment of the best possible health (RAND Foundation, 2010). However, evidence for its impact on improved health status is conceptually difficult to ascertain. A recent survey conducted on behalf of the European Commission's Directorate General for Health and Consumers (2012) found that the term 'patient involvement' was not well understood by neither practitioner nor patient. Furthermore, the respondents (practitioners and patients) could not clearly identify the link or association between improved patient involvement and improved health status. At the same time, many practitioners believed that patient involvement improved the quality of healthcare and posed few risks. The respondents

mentioned the benefits of patient involvement, including patients being more motivated, taking better care of themselves, having better understanding of their conditions and treatments, and monitoring their health themselves.

It is too premature to conclude exactly what effects citizen consultation has had on improving the standard of health of citizens, but consultation should be utilized as an important measure that contributes towards the goal of improving health status and outcomes.

The Council of Europe has taken the initiative to provide a conceptual model platform which will assist Member States in taking measures to improve their engagement with citizens in the planning, management and delivery of healthcare.

One of the main aims of the Council of Europe project "Model of a citizens' consultation platform on the right to the protection of health" is the promotion of citizens' health literacy and health education through the different groups of society.

People limited in health literacy may have difficulties in:
- understanding and using health information such as advice on self-care, instruction for medications, food labels, safety warning, etc.
- accessing services which support their health
- navigating through a complicated heath care systems
- interacting with health care providers.

A Survey on good practices for a citizens' consultation platform on the right to the protection of health has been prepared together with the European Health Literacy Network (EHLN).

The aims of the Council of Europe Survey were:
- to gain a better understanding of the way in which citizens' are consulted their right
- to gather examples of good practice of citizens' participation
- to gather examples of good practice on promoting health literacy through different groups of society.

The Survey was circulated to the Ministries of Health of all Council of Europe member states via the European Committee for Social Cohesion (CDCS). 22 countries have replied to the Survey, shared their experiences and provide examples of good practice.

Draft Model of a Citizens' Consultation Platform

The aim of the Platform is to improve the cooperation of all stakeholders in order to improve the quality and efficiency of relevant instruments, mechanisms and processes.

In the interest of promoting an open and genuine consultation on the right to the protection of health, a consultation platform enables a full and frank discussion about citizens' rights, expectations, views on health care services provided and on various major structural deficiencies in current legislation.

The primary objective of the Model of a Consultation Platform is to develop a plan for dealing with the client's requirements and preferences by consulting them on their rights to the protection of health.

The purpose of this consultation platform is therefore to allow citizens to claim and enjoy their rights to the protection of health, and also to allow potential health and social stakeholders to give their views on the possible establishment of the virtual platform.

This model of the consultation platform is based on mutual work and cooperation of all relevant governmental and non-governmental stakeholders. The concept of the model is an involvement of all health partners, health professionals, decision makers, legal and social structures, their roles and influence on health care expectations.

In order to move the debate about the merits of citizens' consultation forward and to support Member States in taking appropriate measures, the Council of Europe suggests a conceptual model that is made up of the following components:

- **Stakeholders** – patients, citizens, healthcare providers, healthcare professionals, civil society, government, industry.

- **Measures** – in this instance citizens consultation through a variety of different mechanisms, such as surveys, meetings, round tables, citizen panels, advisory councils, patient representation on boards, etc.

- **Objectives** – in line with the European Social Charter the objectives can be threefold: objectives aimed at protecting the health of citizens, objectives aimed at preventing deterioration of the health of citizens and objectives aimed at promoting improved health status amongst citizens.

Since citizens consultation is a complex and multidimensional concept, it requires a clear conceptual platform that can serve as an aid to Member States in understanding and implementing measures to prevent, protect and promote the health status of its citizens.

The central idea is that a consultation platform which brings representatives from all the stakeholders together to work on the achievement of different objectives using various measures will assist Member States in improving their citizens' rights to benefit from measures enabling them to enjoy the highest standard of health attainable.

In the interest of promoting an open and genuine consultation, such a platform will enable a full and frank discussion about citizens' rights, expectations, opinions on health care services provided and what can be done to improve the provision of healthcare in order to achieve the highest standard of health attainable.

In 2011, the Council of Europe embarked on its own consultative process to prepare a draft model for consultation with citizens, with a specific emphasis on health literacy. The diagrams in Appendix 2 contain the Council of Europe proposal for a "Map of determinants of health literacy", showing the main components for citizens' consultation, first in an overview and then in more detail.

This model for consultation is:

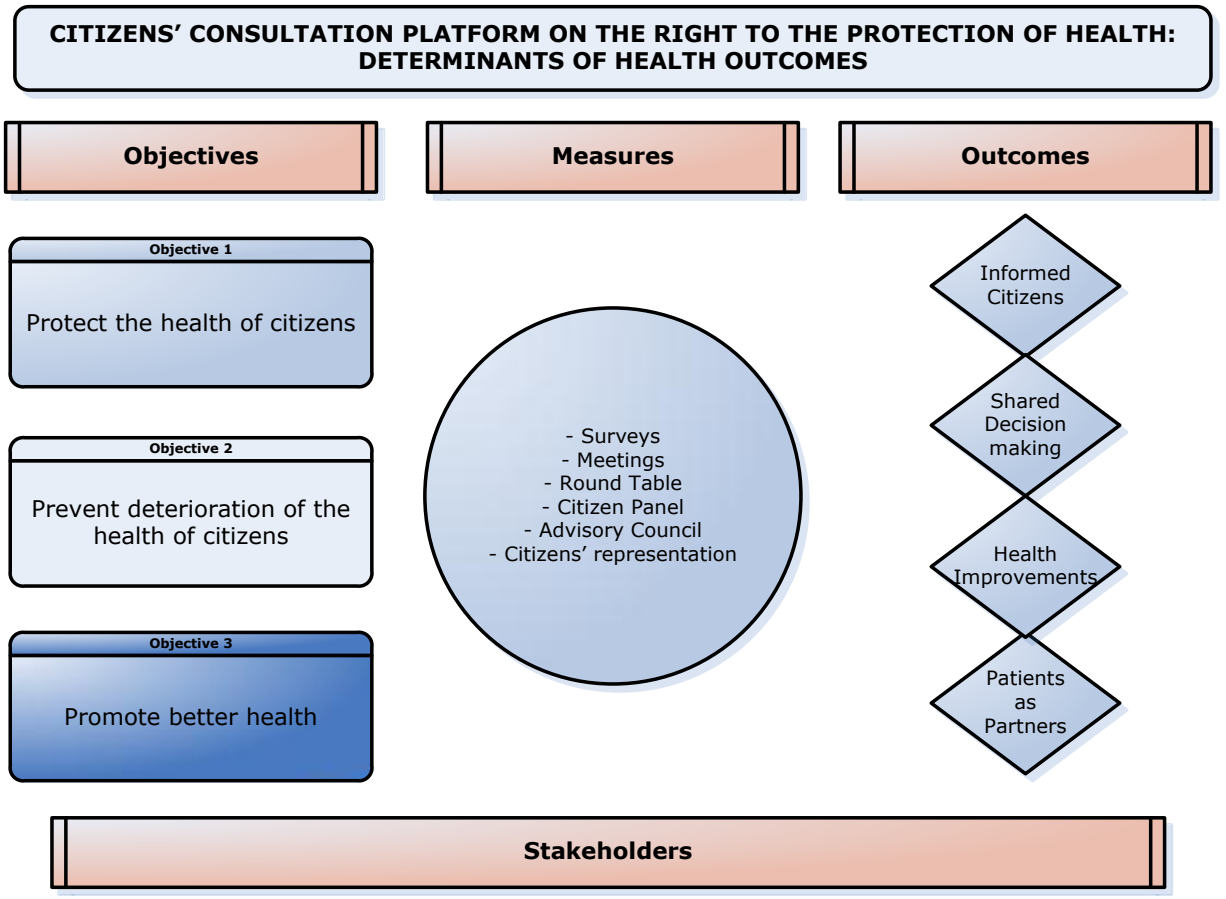
- based on the protection of human rights
- founded on a legal basis (principles of equality and nondiscrimination)
- based on patient protection and safety.

It:

- covers all groups of society, especially vulnerable groups.
- aims to promote health literacy
- advances meaningful citizens' consultation.

On 8-9 November 2012, the Council of Europe organised an International Workshop in Strasbourg, France, to present and discuss the summary report of the survey findings and its proposal of a Model Platform for citizens' consultation on the right to the protection of health. It was attended by about 40 professionals from all relevant disciplines (doctors, health professionals, representatives of the Ministries and Public Health Institutes, members of Parliaments, health networks, etc.) as well as representatives of patient organisations.

Following the analysis of the responses to the survey and the feedback from the Workshop, the Council of Europe prepared a revised conceptual framework – the diagram below illustrates a possible Council of Europe draft Model for a Citizens' Consultation Platform.



The diagram above and the "Map of determinants of health literacy" in Appendix 2 can be used by Member States as a basis for future work in relation to the promotion of citizens' health literacy and health education.

Conclusions

Even though institutions such as the Institute of Medicine and the WHO agree that public (citizen) consultation plays an important role in improving the health status of citizens, several researchers have pointed out that, as a measure, public consultation has remained ill-defined and limited evidence exists of its effectiveness (European Commission, 2012 RAND Foundation, 2010).

This is one of the main reasons why the Council of Europe intends to continue to support its Member States in taking measure designed to enable citizens to enjoy the highest possible standard of health. The proposed draft Model of a Citizens' Consultation Platform will hopefully assist Member States in implementing appropriate measures.

A significant number of strategies, policy documents, charters and legal instruments, at local, regional, national and international level have advocated for the provision of health care systems in Europe that are centered on the needs of people and that the citizen's voices should be listened to (see for example the World Health Organization, Ljublijana Charter, 1996).

Terminology

Health - a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1946)

Health Literacy - the ability to access, understand, appraise and apply information to take decisions concerning health care, disease prevention and health promotion. Being literate on health issues does not necessarily require any special education on health. However, it requires a complex combination of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations (Council of Europe, Introduction to the Survey on citizens' consultation on the right to the protection of health, 2012)

Social cohesion - the capacity of a society to ensure the well-being of all its members - minimising disparities and avoiding marginalisation – to manage differences and divisions and ensure the means of achieving welfare for all members. Social cohesion is a political concept that is essential for the fulfillment of the three core values of the Council of Europe: human rights, democracy and the rule of law. (New strategy and Council of Europe Action Plan for Social Cohesion approved by the Committee of Ministers on 7 July 2010.)

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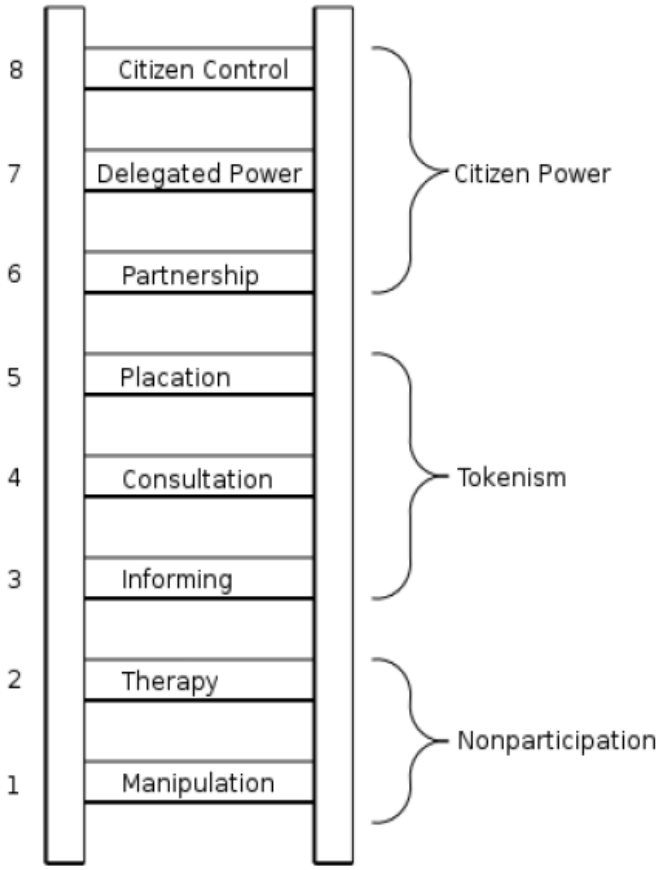
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World Health Organization, 1996, The Ljubljana Charter on Reforming Healthcare

Appendix 1 – Arnstein's Ladder of Citizen Participation

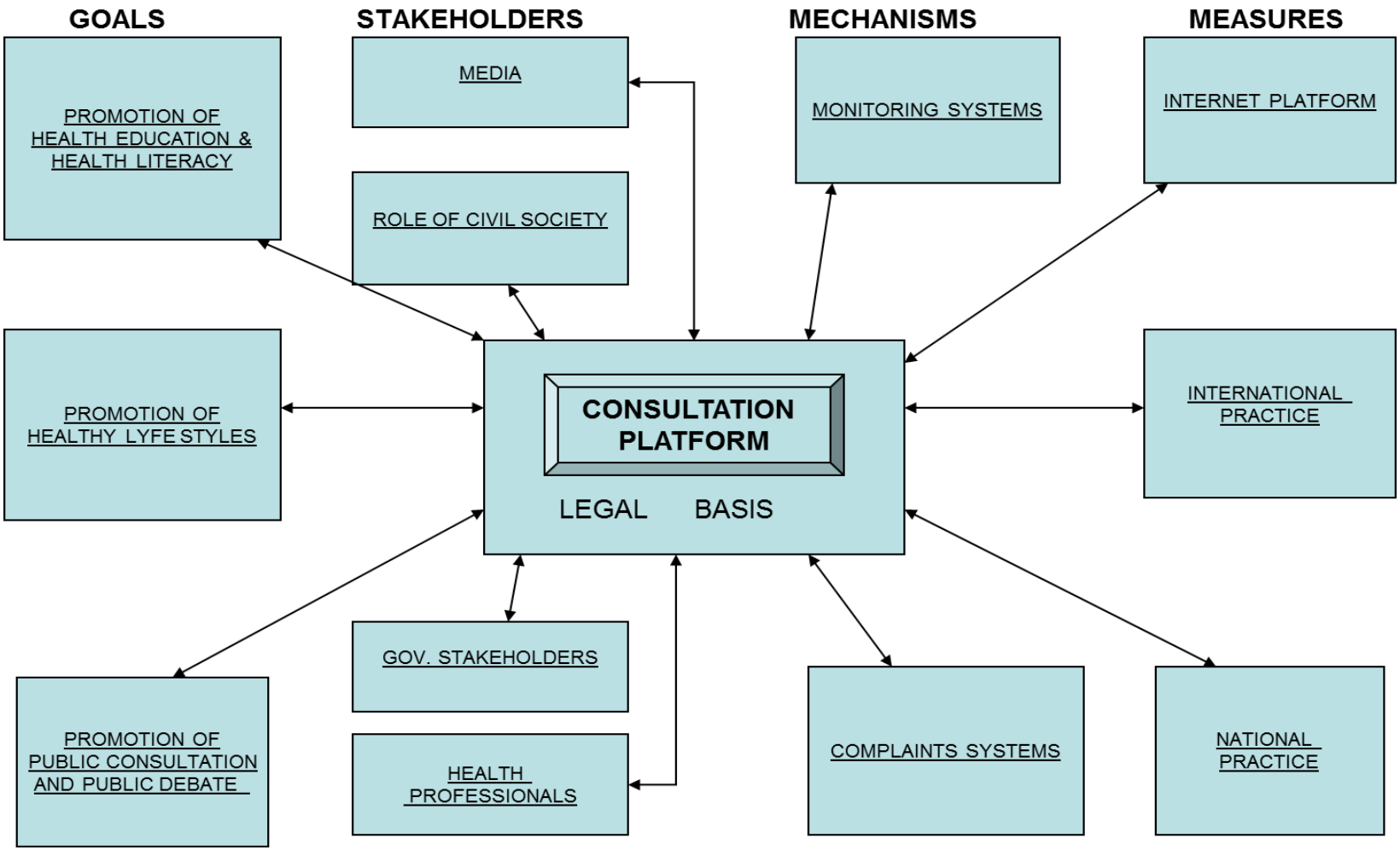


A Ladder of Citizen Participation

Sherry R Arnstein

Appendix 2 –Map of determinants of health literacy

Map of Determinants of Health Literacy (1)
Overview of main components of a consultation platform on the right to the protection of health



Map of Determinants of Health Literacy (2)
Detailed components of a consultation platform on the right to the protection of health

